**SHUAR HEALTH AND LIFE HISTORY PROJECT (SHLHP)**

**TERMS AND CONDITIONS & DATA USER AGREEMENT FORM\***

Version 1.0 (June 15, 2020)

\*modified from <https://www.icpsr.umich.edu/files/ICPSR/pdf/ICPSRRestrictedDataUseAgreement_2018.pdf>

**TERMS AND CONDITIONS**

**I. Role of Principal Investigator & Research Staff**

A. The Principal Investigator (PI) is the person primarily responsible for conducting the research or statistical analyses described in the Research Description (Question 9) of this Data Use Agreement (DUA). Alternatively, the PI supervises the Research Staff conducting the research or statistical analyses described in the Research Description.

B. The Research Staff are all persons at the PI’s Institution, excluding the PI, who will have access to the SHLHP Data obtained through this DUA, including students, other faculty and researchers, staff, agents, or employees for which the PI accepts responsibility.

**II. Responsibilities & Requirements of Principal Investigator**

A. The PI assumes the responsibility of completing this DUA and any other required documents, reports, and amendments. This includes providing updated copies of a document signed by the PI’s Institutional Review Board (IRB), or equivalent, approving or exempting the research project.

B. All shared SHLHP data are fully de-identified. However, the PI assumes the responsibility of ensuring that these data are not shared beyond the PI and Research Staff listed on this agreement, for the purposes so stated.

C. The PI recognizes the potentially sensitive nature of these SHLHP data and understands the responsibility that SHLHP has to protect Shuar participants. When referring to these data, the PI recognizes that in many cases it may not be necessary or appropriate to identify the population specifically as “Shuar” but to instead refer to these data as from “an Indigenous Amazonian population”.

D. PIs must meet each of the following criteria:

1. Have a PhD or other research-appropriate terminal degree (for example, MPH); and

2. Hold a faculty appointment or have an appointment that is eligible to be a principal

investigator at their institution

**III. Obligations of the Investigator, Research Staff, and Institution**

SHLHP data provided under this DUA shall be held by the Investigator, Research Staff, and their Institution in strictest confidence and can be used or disclosed only in compliance with the terms of this Agreement. Additionally, the Investigator, Research Staff, and their Institution agree:

A. That these data will be used solely for purposes directly related to the project as identified in the Research Description of this application (Question 9), and for no other purpose whatsoever without the prior written consent of SHLHP co-directors.

B. That no persons other than those identified in this Agreement (Question 1-4) or in subsequent amendments to this Agreement, as Principal Investigator or Research Staff and who have signed this Agreement or a Supplemental Agreement, be permitted access to the contents of SHLHP Data files.

C. That no attempt under any circumstances will be made to link the SHLHP Data to any individual person/group or community from which the confidential information were derived, whether living or deceased, or with any other dataset, including other datasets provided by SHLHP.

1. There is to be no release of sample population information or characteristics in greater detail than released or published by the researchers who collected the SHLHP Data. This includes but is not limited to publication of maps.

D. That any books, articles, conference papers, theses, dissertations, reports, or other publications that employed SHLHP Data or other resources provided by SHLHP reference the bibliographic citation(s) provided by SHLHP. Moreover, any books, articles, conference papers, theses, dissertations, reports, or other publications are to be reported to SHLHP for inclusion in its data-related bibliography.

1. Typically, it is deemed appropriate for SHLHP personnel who were integral to the data collection process to be included as co-authors on any resulting publications, conference proceedings, and other work products. SHLHP co-directors will work with researchers on a case-by-case basis regarding authorship. In all cases, manuscripts or other works must be reviewed by SHLHP co-directors prior to any submission.

E. To provide an annual update to SHLHP (via email to *shuarproject@gmail.com*) that includes:

1. A copy of the annual IRB approval for the project described in the Research Description;

2. A listing of Research Staff using SHLHP Data for dissertations or theses, the titles of these papers, and the date of completion; and

3. An update on any change in the scope of the project as described in the Research Description.

F. To notify SHLHP of any change in institutional affiliation of the Investigator, a change in institutional affiliation of any Research Staff, or the addition or removal of Research Staff on the research project. Notification must be in writing and must be received by SHLHP at least six (6) weeks prior to the last day of employment with the affiliated institution. Notification of the addition or removal of Research Staff on the research project shall be provided to SHLHP as soon as reasonably possible. Investigator’s separation from their Institution terminates this DUA unless this DUA is transferred to a different institution with appropriate documentation and approvals.

G. Upon PI’s change in institutional affiliation or termination of DUA, PI must provide a written assurance of destruction of all electronic and paper data provided by SHLHP and submit this documentation to SHLHP.

H. That use of the SHLHP Data will be consistent with their Institution’s policies regarding scientific integrity and human subject’s research.

**IV. Violations of this Agreement**

SHLHP Co-Directors will investigate allegations of violations of this DUA in accordance with its policies and procedures on scientific integrity and misconduct. In the event of a breach of any provision of this DUA, SHLHP may:

1. Terminate this Agreement upon notice and require return/destruction of the SHLHP data and any derivatives thereof;

2. Deny PI and/or Research staff future access to SHLHP Data; and/or

3. Report the inappropriate use or disclosure to the appropriate federal and private

Agencies, foundations, and organizations that fund and/or publish scientific and public policy research.

**V. Additional Information**

A.All notices and contractual correspondence under this Agreement on behalf of the Investigator shall be made in writing and emailed to the address below: [shuarproject@gmail.com](mailto:shuarproject@gmail.com)

B. This agreement shall be effective for 24 months from execution and can be extended upon approval by SHLHP Co-Directors. Note that if an annual IRB is required, this must be updated in order for the DUA to remain in effect. Expiration of IRB approval or equivalent automatically voids this DUA.

C. The obligations of Investigator, Research Staff, and Institutional Affiliation set forth within this DUA may not be re-assigned or otherwise transferred without the express written consent of SHLHP.

**DATA USE AGREEMENT (DUA) FORM** *(Complete ALL sections of the DUA below)*

**1. Name of Researcher(s) and Affiliation(s) (if numerous affiliations, list in order of relevance).** *Principal Investigator (PI), who will be responsible for analyzing and interpreting the data, as defined in the Terms & Conditions, should be listed first. A secondary investigator (when applicable) who will be the next point of contact after the PI should be listed next. Additional investigators who will have access to the dataset should be listed below the PI. You can add more rows at the bottom of the list if needed.*

|  |  |  |  |
| --- | --- | --- | --- |
|  | **LAST NAME, FIRST NAME** | **POSITION/TITLE** | **AFFILIATION** |
| I. | Click or tap here to enter text. | Click or tap here to enter text. | Click or tap here to enter text. |
| II. | Click or tap here to enter text. | Click or tap here to enter text. | Click or tap here to enter text. |
| III. | Click or tap here to enter text. | Click or tap here to enter text. | Click or tap here to enter text. |
| IV. | Click or tap here to enter text. | Click or tap here to enter text. | Click or tap here to enter text. |

**2. Contact information for principal investigator (PI) (in Question 1):**

|  |  |  |  |
| --- | --- | --- | --- |
|  | **PI MAIN MAILING ADDRESS** | **PI EMAIL ADDRESS** | **PI PHONE NUMBER** |
| I. | Click or tap here to enter text. | Click or tap here to enter text. | Click or tap here to enter text. |

**3. Contact information for secondary investigators (if applicable) (in Question 1).** *A secondary investigator is the next point of contact after the PI.*

|  |  |  |  |
| --- | --- | --- | --- |
|  | **SECONDARY INVESTIGATOR MAILING ADDRESS** | **SECONDARY INVESTIGATOR EMAIL ADDRESS** | **SECONDARY INVESTIGATOR PHONE NUMBER** |
| I. | Click or tap here to enter text. | Click or tap here to enter text. | Click or tap here to enter text. |

**4. Contact information for additional research staff, including students (if applicable) (in Question 1).**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **STAFF NAME**  *(LISTED IN QUESTION 1)* | **STAFF MAILING ADDRESS** | **STAFF EMAIL ADDRESS** | **STAFF PHONE NUMBER** |
| I. | Click or tap here to enter text. | Click or tap here to enter text. | Click or tap here to enter text. | Click or tap here to enter text. |
| II. | Click or tap here to enter text. | Click or tap here to enter text. | Click or tap here to enter text. | Click or tap here to enter text. |

**5. List the journal publication citation(s) (available on *shuarproject.org*) for the dataset that you are interested in accessing.**

Click or tap here to enter text.

**6. Do you require the entire dataset used in the publication Yes/No  or only selected variables Yes/No ? If you chose YES to** ***“selected variables”,* please identify which variables you are interested in below.**

Click or tap here to enter text.

**7. How do you plan to use the SHLHP data that you are requesting under this DUA? Examples of acceptable responses include “check statistical analyses”, “for publication purposes”, “for comparative purposes”, “to inform policy”.**

Click or tap here to enter text.

**8. All SHLHP research involves potentially sensitive human subjects data from a minority Indigenous population and, therefore, IRB approval, exemption, or determination are required for the data you are requesting. A copy of the IRB documentation must be submitted along with this DUA. *Data will not be released until appropriate IRB documentation or equivalent is provided.* In some cases, a letter from an IRB official (or equivalent) documenting that IRB approval is not required is sufficient.**

* 1. **IRB status?**Click or tap here to enter text.
  2. **If approved, IRB protocol title and number:** Click or tap here to enter text.

**9. A copy of IRB-approved or submitted research plan or equivalent for research to be conducted with the SHLHP data is required. This description could also take the form of research questions/hypotheses or a more detailed research proposal (if more space is needed, please provide an attachment to your email).**

Click or tap here to enter text.

**10. SHLHP research required extensive logistical, financial, and personal investment and long-term collaboration among researchers and Shuar. It was carried out under specific co-authorship agreements that apply to any and all data usage. Therefore, relevant SHLHP personnel must be included as co-authors on any resulting publications, conference proceedings, and other work products. In all cases, final manuscripts or other works must be reviewed by SHLHP co-directors prior to any submission as outlined in the Terms & Conditions.**

**Please initial here, and by signing this document (below) you agree to abide by these terms.**

**PI Initials:** Click or tap here to enter text.

**Principal Investigator Certification: I certify that the information I have provided about the project is accurate. Furthermore, I certify that I will direct this project in compliance with SHLHP, and with all applicable laws and regulations.**



**Date:** Click or tap here to enter text.

*E-mail this DUA and other supporting documents to* [*shuarproject@gmail.com*](mailto:shuarproject@gmail.com) *with the Subject Line: SHLHP Data Request. You will be contacted within 3-5 business days.*