

## **ENDURING VOICES PROJECT ETHICS STATEMENT**

### **Photographic Ethics standards for the Enduring Voices Project**

All photographs and video taken of cultural and tribal people, as well as images of the land—including sacred lands—have been taken with strict permission from those individuals, and from the traditional owners of the land that we have been invited onto. For any images that are deemed suitable for media use, permission has been given for specific usage. In addition the names of individuals, their tribal affiliation, and their land names have been carefully documented and included in captions where appropriate. We understand the photographing of people and their land is an act of trust and is completed with respect and understanding to the laws and traditions of the people involved. The Enduring Voices Project film and photography archive has been designed to be an archive of culture for future generations.

### **Policy on the Protection of Human Research Subjects**

In accordance with the Federal Department of Health and Human Services Basic Policy on the Protection of Human Research Subjects, 45 C.F.R. § 46 (1991), the Living Tongues Institute for Endangered Languages (and the Enduring Voices Project, which is a collaboration between Living Tongues and National Geographic) has adopted the following policy and protocols with respect to the protection of the rights and welfare of human research subjects who participate in the projects conducted by, or under the supervision of, our staff and associates. The Living Tongues Institute for Endangered Languages believes in the importance of protecting the welfare, rights and privacy of the participants in every research project we undertake and has adopted a statement of research ethics that requires informed consent from all participants, implemented safeguards to ensure the confidentiality of information related to project participants, and notification of all project participants of the nature of the risks that such projects may entail. Living Tongues Institute for Endangered Languages has an established protocol such that all of our projects are subject to an extensive process of internal review as well as meeting stated policies of external funding agencies, as well as collaborating or host institutions. We obtain written and/or oral (filmed) consent from all participants for the use of all elicited research data.

#### Non-Discrimination

The Living Tongues Institute for Endangered Languages is committed not to discriminate on the basis of race, color, religion, sex, national origin, primary language or other characteristics of speech, disability, age, marital status, sexual orientation or veteran status.

#### Institutional Review Board

All research involving human participants—which includes most projects carried out by the Living Tongues Institute for Endangered Languages—is subject to a careful review process by our Institutional Review Board, which meets in advance of the undertaking of any project and throughout the course of such project, pursuant to which our Institutional Review Board ensures that (a) the methods used and modes of research provide

adequate protection of the welfare, rights and privacy of the project participants at all times throughout the project and (b) the project complies with relevant Federal and other institutional standards.

Our Institutional Review Board is presently comprised of Dr. Gregory D.S. Anderson, Ph.D., president of the Living Tongues Institute for Endangered Languages and adjunct assistant professor of linguistics at the University of Oregon, Eugene; Dr. K. David Harrison, PhD, our vice president and assistant professor of linguistics at Swarthmore College, Swarthmore, PA; James M. Faulkner, principal of Highland Asset Management, Portland, OR; our Treasurer, Jonathan M. Anderson, Esq. of Torys LLP, New York, NY, our attorney and brother of Dr. Anderson; and Dr. Gregory C. Dillon, MD, a New York psychiatrist.

Our Institutional Review Board has established procedures for each research project undertaken by the Living Tongues Institute for Endangered Languages which require that:

(i) all participants taking part in the project are appropriate for the particular project undertaken;

(ii) any risk to which any participant may be subjected is minimized by using all appropriate measures under the circumstances and is reasonable with respect to anticipated benefits;

(iii) adequate provision is made for confidentiality of data and anonymity of each participant in any published or publicly presented record;

(iv) adequate provision is made for obtaining informed consent from all participants, which consent shall be obtained from such participants in writing and/or on digital video recording;

(v) all participants have been made aware of the types of risk that they may be exposed to in such research projects, including any potential physical, economic, legal, psychological and social risks;

(vi) all participants have voluntarily given informed consent to participate in a way that honestly informs participants of the purpose and potential risks and benefits of the research;

(vii) all participants have been informed about the steps that are undertaken to protect their privacy and confidentiality;

(viii) all participants have been informed about any benefit to be derived from participation in the research.

(ix) all records will be retained for at least three years after completion of the research project, including, without limitation, informed consent documentation, research proposals, progress reports, and all related correspondence concerning human participants;

(x) adequate special provisions have been made for participants, if any, who are physically, mentally, economically, or educationally disadvantaged; and

(xi) our selection of participants has been made in compliance with our non-discrimination policy, including a specific required justification from an investigator whenever the participant population is restricted to one gender or age group.

Prior to approving a project, our Internal Review Board establishes specific procedures for the project to determine (a) if a review of the project by the Internal Review Board is required more frequently than annually or whether third party independent verification is necessary, (b) to whom on the Internal Review Board or at the Institute an investigator must report in the event the nature of the research projects has sufficiently changed during the course of the project to require re-approval or suspension of approval, as well as the prompt reporting of the appearance of unanticipated risks to the participants.

Our Internal Review Board further requires that the informed consent delivered by a project participant (a) be the only record linking such participant to the research, (b) includes an acknowledgment that such participant has been informed about the risks and potential harms, if any, that would result from a breach of confidentiality with respect to such informed consent, (c) whether such participant is willing to allow documentation linking such participant with the research, and that such participant's wishes shall govern; and (d) the research presents no more than minimal risk of harm to subjects. Our Internal Review Board may permit a waiver to the foregoing procedures with respect to certain projects in which the research involves minimal risk, the rights and welfare of the participants are not adversely affected, and the research would not be feasible without such waiver.

#### Basic Elements of Informed Consent

Informed consent is the agreement obtained from a participant, or from an authorized representative, for such person's participation in a project activity. The agreement, written or oral, entered into by the subject, may include no exculpatory language through which such participant waives, or appears to waive, any of such person's legal rights, or to release any researcher, investigator, sponsor, the Living Tongues Institute for Endangered Languages or its representatives, agents or staff from liability for gross negligence or willful misconduct.

Documented informed consent will consist of a written or filmed oral consent, the form of which has been approved by our Institutional Review Board, and signed by the participant or such person's legally authorized representative. A copy of any written informed consent shall be given to the person signing the form and the participant and be in both English and a foreign language comprehensible to such participant, if such participant does not speak or understand English. Written consent forms may be read to the participant or such person's legally authorized representative, but the investigator shall give either the participant or the representative adequate opportunity to read it before it is signed.

For participants in projects by the Living Tongues Institute for Endangered Languages, informed consent shall consist of the following basic components:

(i) a statement that identifies the exercise as a research activity, provides an explanation of the purpose(s) of the research, details the methods to be followed and estimates the duration of the subject's participation.

(ii) a statement describing the extent to which confidentiality of records identifying the subject will be maintained and allowing them the opportunity to scale or control this access as they deem appropriate;

(iii) a description of any reasonably foreseeable risks or discomforts to the

subject;

(iv) a description of any benefits to the subject or to others that may reasonably be expected from the research;

(v) a statement that participation is voluntary, refusal to participate will involve no penalty or loss of benefits to which the subject is otherwise entitled, and that the subject may discontinue participation at any time without penalty or loss of benefits to which the subject is otherwise entitled;

(vi) an explanation as to whether any compensation will be offered for their participation and the terms of such compensation; and

(vii) a statement regarding compensation and medical treatment with a meaning substantially similar to the following:

“I understand the Living Tongues Institute for Endangered Languages does not provide a research participant with compensation or medical treatment in the event I am injured as a result of such participation in the research project.”

### Certain Definitions

Federal regulations define “minimal risk” as follows:

“The probability and magnitude of harm or discomfort anticipated in the research are not greater in and of themselves than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests.” Generally, a project involves minimal risk if:

- (i) the participant experiences no pain or physical danger or risk thereof;
- (ii) the participant experiences no emotional arousal or psychological stress beyond the levels normally to be expected in everyday life;
- (iii) the project neither induces nor attempts to induce long-term significant change in the participant’s behaviors (including attitudes toward self and others);
- (iv) the elicited research data would not embarrass or socially disadvantage the participant, were confidentiality to be violated; and
- (v) if the investigator conceals information about the specific purpose of the project, there is no reason to believe the participant would choose not to participate if s/he had known that information initially.

For purposes hereof the following definitions shall apply:

(a) physical risk

Physical discomfort, pain, injury, illness or disease brought about by the methods and procedures of the research.

(b) legal risk

Risk of criminal prosecution or civil lawsuit when research methods reveal that the participant has or will engage in conduct for which the participant or others may be criminally or civilly liable.

(c) psychological risk

Psychological effects may be experienced during the research situation and/or later, as a result of participation, including, without limitation, anxiety, stress, fear, confusion, embarrassment, depression, guilt, shock, loss of self-esteem or altered behavior.

(d) social/economic risk

Alterations in relationships with others that are to the disadvantage of the participant, including embarrassment, loss of respect of others, labeling with negative consequences, or diminishing the participant's opportunities and powers in relation to others. Economic risks may include payment by subjects for procedures, loss of wages or income and damage to employability.

(e) loss of confidentiality

Confidentiality is presumed and will be maintained unless the investigator obtains the express permission of the participant to do otherwise. Risks include invasion of privacy, as well as the social, economic and legal risks outlined above.