

Journey of Transformation Curriculum for Native American Adolescents (JOT)

NCT05274217

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Parent / Guardian Permission Form

IRB Approved 02/08/2023

**UNIVERSITY OF WASHINGTON**  
**Guardian Permission**  
**JOURNEY OF TRANSFORMATION**

Researchers:

- Teresa Evans-Campbell, Associate Professor, School of Social Work, University of Washington, 206-849-9463, tecamp@uw.edu

We are asking your permission for your child to be in a research study. This form gives you information to help you decide whether or not you would like them to join the study. Being in the study is completely voluntary. Please read this carefully. You may contact Teresa Evans-Campbell and ask any questions about the study. Then you can decide whether or not you want your child to join the study.

**KEY INFORMATION ABOUT THIS STUDY**

You may want your child to participate in the study as they will hear traditional stories from Native American Elders regarding health behaviors, they will engage in traditional activities such as drum making and storytelling vest making, they can create a digital story promoting wellness and they will be taught leadership skills. You may not want your child to participate as we will talk about how to reduce or avoid substance use and develop healthy relationships. In this study we are assessing if Native teachings can promote health behaviors and leadership skills. We are collecting information about your child's health behaviors, connection to others, cultural connections as well as substance use and sexual health. Activities include listening to Elder stories about health, making drums, making a story telling vest, creating a digital story on health promotion, and going on 1 to 2 field trips to cultural settings near [REDACTED] School. We will develop a new curriculum that will be made available to the general public and may help improve the health and wellness of Native American youth across the country. The risks associated with participation in this study are primarily related to the loss of privacy and unintentional release of private information. Your child may feel embarrassed or uncomfortable answering some of the survey questions. Your child will be told they can skip any question they do not want to answer. Participation in this study is completely voluntary and you may withdraw your child at any time. If you do not want your child to participate in this research, they will be assigned to a class that does not offer the program.

**PURPOSE OF THE STUDY**

In this study we are developing a teaching guide based on traditional storytelling and traditional activities to enhance youth leadership skills and healthy decision making around health, healthy relationships, prevention of substance use, and making healthy choices related to sexual health.

**STUDY PROCEDURES**

If you agree for your child to be in this study, their health class will be assigned by chance [randomly like flipping a coin] to start the research program in the fall or to start the research program in the winter. As part of the study, your child will take a survey and will be informed that they may skip any survey questions they do not want to answer. We will also share that all

activities and surveys are voluntary. During the semester your child receives the program, the class will:

Week 1. Take a 20 minute online survey about healthy relationships, drug use, youth leadership skills and connecting with Native communities.

Weeks 1-3. Meet up to set goals around health, healthy relationships and how to reduce or avoid alcohol, tobacco, or other drug use.

Weeks 1 – 8 (months 1-2). As part of the class, attend 8 health sessions on healthy behaviors and health promotion. Learn new skills around youth leadership, storytelling, and traditional health practices. The sessions will highlight connecting to tribal traditions.

Month 3. Take an online check-in survey via a link sent to your child's email address.

Month 6. Take an online check-in survey via a link sent to your child's email address.

Month 12. Take an online check-in survey via a link sent to your child's email address.

### **Optional after school activities**

Week 9- 16 (months 3-4). Attend a once-a-month activity to help build leadership skills. Activities are between 1-2 hours after school and include drum making, film making, creating a storytelling vest that incorporates their own cultural symbols, and up to two outdoor field trips. The field trips are to places of cultural significance near the school and involve a 30-45 minute hike.

Week 16 (month 4). Meet with a study educator for a session to revise goals for health and community leadership.

Week 9 -24 (months 3 - 6). Attend a 2-hour digital storytelling training and three-monthly planning sessions to prepare for an optional digital storytelling leadership night. The story can be about what your child has learned about health promotion, traditional health practices, and to celebrate their health leadership journey.

Week 25 (month 6). Attend the leadership night and present their digital stories if your child would like. Help prepare a traditional feast and giveaway that will honor their community culture and values.

**Health survey questions.** The survey will ask questions about your child's health behaviors, connection to others, cultural connections as well as substance use and sexual health.

Examples of some of the most sensitive questions your child will be asked to answer in the survey are: "During last 12 months have you had sexual intercourse with other youth" and "During the past month, what was the most you had to drink in any one day." Your child's answers will be directly linked to a study ID number and not directly linked to the child's name. Your child is free to not answer any questions that they do not want to answer.

**Your child's participation in this study is voluntary.** Participation throughout this research study is completely voluntary and confidential. Your child is free to withdraw from this study at any time without any repercussions.

### **RISKS, STRESS, OR DISCOMFORT**

Potential risks: Your child may also worry about people finding out what they say in the survey or activities. There is a risk of loss of confidentiality (i.e., someone outside the study finding out

personal information). We have taken several steps to protect your child from these risks. Survey data will be kept confidential and will not be directly linked to your child's name. The data is stored on a secured server, password protected link file.

Your child will be asked about thoughts, feelings, and personal difficulties that may be private and feel sensitive. They may feel embarrassed or anxious if they choose to disclose personal information. Some questions they will be asked are related to substance use, trauma exposure, health behaviors and about potentially illegal behaviors such as substance use. These questions may make them feel uncomfortable, bring back stressful or upsetting memories or seem intrusive. If they experience an increase in emotional distress related to their participation, they are asked to please let study staff know so that we can provide appropriate support.

During the optional outdoor activities, your child may feel environmentally-based discomfort related to heat or rain exposure, limited bathroom access, walking on some unpaved roads, roads with hills, curves, or construction work, as well as exposure to insects such as mosquitos, wildlife such as snakes, and flora or fauna such as poison oak or ivy. At any time, if your child needs a break, vehicles will be in close proximity for easy access, extra hydration, and rest and vehicles to transport more significant injuries to appropriate medical resources. As a [REDACTED] student, your child can access the IHS health clinic services on campus free of charge.

#### **ALTERNATIVES TO TAKING PART IN THIS STUDY**

If you do not want your child to join the study, they will have the option to stay in the class, but will not be asked to take the surveys.

#### **BENEFITS OF THE STUDY**

Your child may want to join this study as they will hear traditional stories from elders regarding health behaviors, they will engage in traditional activities such as drum making and storytelling vest making, they can create a digital story promoting wellness and they will be taught leadership skills. Your child may also feel good about helping an effort that is aimed at improving the health and wellness of Native American youth across the country.

#### **COMPENSATION**

Your child will be paid up to \$95 in online gift cards for completing the online check-in surveys. They will receive \$20 for taking the first survey; \$20 for taking the second survey; \$25 for taking the third survey; and \$30 for taking the final survey.

#### **SOURCE OF FUNDING**

The study team is receiving financial support from the National Institute for Drug Abuse.

#### **CONFIDENTIALITY OF RESEARCH INFORMATION**

The information your child gives us will be used for research purposes only and will be kept private. Names and other personal identifying information will not be put directly on the survey. Instead, the survey data will be given an ID number, and the ID number will be linked to names and identifiers on a list that will be kept separate from the data in a secure location. The study team will not share the child's survey responses with parents.

#### **OTHER INFORMATION**

You may refuse to allow your child to participate and you are free to withdraw your child from this study at any time without penalty or loss of benefits to which you or your child are otherwise entitled.

We will receive community approval before publishing or presenting any of the results. In any sort of report we might publish, we will not include any information that will make it possible to identify a person. If you would like to see a copy of the final report once the study is finished, you can contact Dr. Tessa Evans-Campbell, 206-849-9463 at the University of Washington Indigenous Wellness Research Institute.

A description of this clinical trial will be available on <http://www.clinicaltrials.gov>, as required by U.S. Law. This Web site will not include information that can identify you. At most, the Web site will include a summary of the results. You can search this Web site at any time.

We have a Certificate of Confidentiality from the National Institutes of Health. This helps us protect your child's privacy. The Certificate means that we do not have to give out information, documents, or samples that could identify your child even if we are asked to by a court of law. We will use the Certificate to resist any demands for identifying information. We can't use the Certificate to withhold your child's research information if you give your written consent to give it to an insurer, employer, or other person. Also, you or a member of your family can share information about yourself or your part in this research if you wish.

There are some limits to this protection. We will voluntarily provide the information to:

- a member of the federal government who needs it in order to audit or evaluate the research;
- individuals at the institution(s) conducting the research, the funding agency, and other groups involved in the research, if they need the information to make sure the research is being done correctly;
- the federal Food and Drug Administration (FDA), if required by the FDA;
- individuals who want to conduct secondary research if allowed by federal regulations and according to your consent for future research use as described in this form;
- authorities, if we learn of child abuse, elder abuse, or your child's intent to harm themselves or others.

The Certificate expires when the NIH funding for this study ends. Currently this is 4/1/2025. Any data collected after expiration is not protected as described above. Data collected prior to expiration will continue to be protected.

You will not receive any results from allowing your child's data to be placed in the Indigenous Wellness Research Institute data bank. This data bank is an internal data bank managed by the Indigenous Wellness Research Institute at the University of Washington.

The information that we obtain for this study may be used for future studies. We will remove anything that might identify your child from the information. The study information might then be used for future research studies or given to another investigator without getting additional permission from you.

Subject's statement

The study has been explained to me. I volunteer my child to take part in this research. I have had a chance to ask questions. If I have questions later about the research, or if I or my child have been harmed by participating in this study, I can contact one of the researchers listed on the first page of this consent form. If I have questions about my child's rights as a research subject, I can call the Human Subjects Division at (206) 543-0098 or call collect at (206) 221-5940. I will receive a copy of this permission form.

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Printed name of child

Date

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Printed name of parent

Signature of parent

Date

When parent/guardian will make their mark to provide permission:

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Printed name of witness

Signature of witness

Date

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Relationship of witness to parent/guardian

Copies to:     Researcher  
                    Parent/guardian