

# Communicating Results of a Dietary Exposure Study Following Consumption of Traditionally Smoked Salmon

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## ABSTRACT

One expectation of community-based participatory research (CBPR) is participant access to study results. However, reporting experimental data produced by studies involving biological measurements in the absence of clinical relevance can be challenging to scientists and participants. We applied best practices in data sharing to report the results of a study designed to explore polycyclic aromatic hydrocarbons absorption, metabolism, and excretion following consumption of traditionally smoked salmon by members of the Confederated Tribes of the Umatilla Indian Reservation (CTUIR). A dietary exposure study was developed, in which nine Tribal members consumed 50 g of traditionally smoked salmon and provided repeated urine samples over 24 hours. During recruitment, participants requested access to their data following analysis. Disclosing data is an important element of CBPR and must be treated with the same rigor as that given to the data analysis. The field of data disclosure is relatively new, but when handled correctly can improve education within the community, reduce distrust, and enhance environmental health literacy. Using the results from this study, we suggest mechanisms for sharing data with a Tribal community.

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## INTRODUCTION

WITHIN A COMMUNITY-BASED PARTICIPATORY RESEARCH (CBPR) framework, there is an expectation that data will be shared with participants and the community.<sup>1</sup> There is a secondary expectation that data will be presented in an informative and easy to understand format. Yet, sharing environmental or biomedical data with participants can be challenging to researchers because it requires communication of nuanced toxicological, biological, and chemical details. Furthermore, studies are

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<sup>1</sup>R. Morello-Frosch, *et al.* "Toxic Ignorance and Right-to-Know in Biomonitoring Results Communication: A Survey of Scientists and Study Participants." *Environmental Health* 8 (2009). DOI: 10.1186/1476-069X-8-6.

often conducted to learn new information and/or when human health effects are unknown or unclear.<sup>2,3,4,5,6</sup>

Data sharing is even more important when collaborating with Native American communities, as there have been several unfortunate incidents where researchers have misused Tribal data.<sup>7</sup> For example, in 1989, the Havasupai Tribe reached out to an anthropologist at Arizona State University to investigate a genetic link to diabetes within the tribe.<sup>8</sup> The Havasupai contributed biological samples with the belief that the samples would be used exclusively for diabetes research. Unfortunately, the samples were also analyzed to evaluate schizophrenia, inbreeding, and migration theories without consent of the Havasupai.<sup>9</sup> Situations such as these have created mistrust between scientists and Native Americans, which creates a barrier to further scientific endeavors.

One approach to overcoming this barrier is developing a Material Data Sharing Agreement (MDSA) between Tribes and scientists. The MDSA specifies the research projects, limits use of data to those projects, and requires Tribal approval for all additional proposed uses of the data.<sup>10</sup> The benefit of a MDSA is threefold. First, and most importantly, a MDSA recognizes and respects tribal sovereignty, a key principle in conducting CBPR with tribal communities,<sup>11,12</sup> which has the added benefit of building cultural capacity within the researchers and scientific capacity within Tribes. Second, this approach

helps prevent harmful miscommunications;<sup>13</sup> and third, potential participants are made aware of how the samples will be treated and returned.

In addition to a MDSA, CBPR guidelines speak of having a “gatekeeper,” an individual who works with Western researchers to build cultural capacity and ensure that research projects are conducted in a culturally appropriate manner.<sup>14</sup> This gatekeeper ensures that the interpretation of any study respects Tribal customs and practices. This is particularly important in environmental health studies because Native American lifestyles are closely entwined with their natural environment and traditional cultural practices, which create complex exposure pathways that are not well described and often overlooked by environmental managers.<sup>15,16,17,18,19</sup>

### A TRIBAL-UNIVERSITY PARTNERSHIP

The Confederated Tribes of the Umatilla Indian Reservation (CTUIR) is a union of the Cayuse, Umatilla, and Walla Walla tribes, located in Pendleton, OR.<sup>20</sup> CTUIR is governed by the Board of Trustees, which oversees all CTUIR organizations, including the Department of Science and Engineering (DOSE). DOSE personnel began working with Oregon State University (OSU) faculty in 2003 to evaluate tribal exposure scenarios funded by a U.S. Environmental Protection Agency (EPA) Science to Achieve Results (STAR) grant. The tribal–university partnership continued to develop with expanded scientific studies within the Community Engagement Core of the EPA/National Institute of Environmental Health Sciences (NIEHS) Superfund Center at OSU (Table 1). The partnership has previously been described as unique in its approach to address environmental concerns while simultaneously expanding scientific and cultural capacity.<sup>21</sup>

<sup>2</sup>R. Morello-Frosch, *et al.* “Toxic Ignorance and Right-to-Know in Biomonitoring Results Communication: A Survey of Scientists and Study Participants.” *Environmental Health* 8 (2009). DOI: 10.1186/1476-069X-8-6.

<sup>3</sup>J.G. Brody, *et al.* “Reporting Individual Results for Biomonitoring and Environmental Exposures: Lessons Learned from Environmental Health Communication Case Studies.” *Environmental Health* 13 (2014): 40.

<sup>4</sup>S.C. Dunagan, *et al.* *When Pollution is Personal: Handbook for Reporting Results to Participants in Biomonitoring and Personal Exposure Studies.* (Newton, MA: Silent Spring Institute, 2013).

<sup>5</sup>A.D. Hernick, *et al.* “Sharing Unexpected Biomarker Results with Study Participants.” *Environmental Health Perspectives* 119 (2010): 1–5.

<sup>6</sup>J.G. Brody, *et al.* “Improving Disclosure and Consent: ‘Is It Safe?’: New Ethics for Reporting Personal Exposures to Environmental Chemicals.” *American Journal of Public Health* 97 (2007): 1547.

<sup>7</sup>S. Moodie. “Power, Rights, Respect and Data Ownership in Academic Research with Indigenous Peoples.” *Environmental Research* 110 (2010): 818–820.

<sup>8</sup>L.E. Wolf. “Advancing Research on Stored Biological Materials: Reconciling Law, Ethics, and practice.” *Minnesota Journal of Law, Science & Technology* 11 (2010): 99–156.

<sup>9</sup>K. Drabiak-Syed. “Lessons from Havasupai Tribe v. Arizona State University Board of Regents: Recognizing Group, Cultural, and Dignity Harms as Legitimate Risks Warranting Integration into Research Practice.” *Journal of Health & Biomedical Law* 6 (2010): 175.

<sup>10</sup>A. Harding, *et al.* “Conducting Research with Tribal Communities: Sovereignty, Ethics and Data-Sharing Issues.” *Environmental Health Perspectives* 120 (2011): 11–24.

<sup>11</sup>D. LaVeaux and S. Christopher. “Contextualizing CBPR: Key Principles of CBPR meet the Indigenous research context.” *Pimatisiwin* 7 (2009): 1–1.

<sup>12</sup>A. Kelley, *et al.* “Research Ethics and Indigenous Communities.” *American Journal of Public Health* 103 (2013): 2146–2152.

<sup>13</sup>S. Moodie. “Power, Rights, Respect and Data Ownership in Academic Research with Indigenous Peoples.” *Environmental Research* 110 (2010): 818–820.

<sup>14</sup>D. LaVeaux and S. Christopher. “Contextualizing CBPR: Key Principles of CBPR Meet the Indigenous Research Context.” *Pimatisiwin* 7 (2009): 1–1.

<sup>15</sup>S.G. Harris and B.L. Harper. “A Native American Exposure Scenario.” *Risk Analysis* 17 (1997): 789–795.

<sup>16</sup>S.G. Harris and B.L. Harper. “Exposure Scenario for CTUIR Traditional Subsistence Lifeways.” (Department of Science and Engineering, Confederated Tribes of the Umatilla Indian Reservation, Pendleton, OR; 2004).

<sup>17</sup>B. Harper, *et al.* “Subsistence exposure scenarios for tribal applications.” *Human and Ecological Risk Assessment* 18 (2012): 810–831.

<sup>18</sup>B.L. Harper, *et al.* *Traditional Tribal Subsistence Exposure Scenario and Risk Assessment Guidance Manual.* EPA-Star-J1-R831046. (Corvallis, OR: Oregon State University, 2007).

<sup>19</sup>J. Donatuto and B.L. Harper. “Issues in Evaluating Fish Consumption Rates for Native American Tribes.” *Risk Analysis* 28 (2008): 1497–1506.

<sup>20</sup>Confederated Tribes of the Umatilla Indian Reservation. 2014. *Quick Facts.* [http://ctuir.org/system/files/INFO%20PACKET%20COMBINED\\_0.pdf](http://ctuir.org/system/files/INFO%20PACKET%20COMBINED_0.pdf). Accessed June 19, 2015.

<sup>21</sup>B.E. Anderson, M.F. Naujokas, and W.A. Suk. “Interweaving Knowledge Resources to Address Complex Environmental Health Challenges.” *Environmental Health Perspectives* 123:1095–1099. (2015).

Of particular interest to DOSE and CTUIR was research projects designed to evaluate the implications of a polluted environment on the traditional foods consumed by the tribe.<sup>22</sup> Studies of indigenous health, as well as interviews with tribal members, reveal the necessity of evaluating risk assessments within the context of a holistic understanding of health.<sup>23,24,25,26,27,28</sup> Tribal communities often evaluate health and risk as the comprehensive whole of their eco-cultural system, which encompasses the community, the environment, and natural and cultural resources.<sup>29</sup> As such, traditional risk assessments are often inadequate, as they may underestimate consumption rates or may not reflect tribal practices, tribal health co-risk factors, or the eco-cultural system.<sup>30,31,32</sup>

For example, many indigenous people living along major waterways have very high fish consumption rates. The CTUIR lies next to the Columbia River and its tributaries and the average CTUIR subsistence fish consumption rate for adults is estimated to be 540 g per day.<sup>33</sup> The EPA typically assigns a default fish consumption rate of 17.5 g per day,<sup>34</sup> but EPA Region 10

now proposes a more protective rate of 175 g per day, as used by the state of Oregon.<sup>35,36</sup> Since intake rates strongly influence the quantification of human health risk, Tribal populations are concerned that any dietary exposure study in a traditional food will lead risk managers to recommending reduction in intake as the primary way of reducing individual risk without taking into consideration the cultural significance of traditional food for Native Americans.<sup>37,38,39</sup> Traditional foods represent the complex interconnectedness of cultural and traditional practices, ceremony, knowledge transmission, and nutrition.<sup>40,41</sup> Therefore, a stipulation in the CTUIR-OSU MDSA stated that any recommendations developed to reduce risk posed by environmental chemicals would focus on improving health without adversely affecting cultural practices.

### CBPR TO EVALUATE DIETARY POLYCYCLIC AROMATIC HYDROCARBON EXPOSURE

Previously, DOSE and OSU measured polycyclic aromatic hydrocarbons (PAHs) in salmon before and after, hot smoking, and in the urine of the individuals who smoked the salmon. For this project, analytical chemists at OSU developed an improved analytical method to measure 32 PAHs.<sup>42,43</sup> The study found the smoking process increased the concentration of 21 different PAH compounds at levels significantly higher

<sup>22</sup>M.B. Schure, *et al.* "Perceptions of the Environment and Health Among Members of the Confederated Tribes of the Umatilla Indian Reservation." *Environmental Justice* 6 (2013): 115–120.

<sup>23</sup>S.G. Harris and B.L. Harper. "A Native American Exposure Scenario." *Risk Analysis* 17 (1997): 789–795.

<sup>24</sup>S.G. Harris and B.L. Harper. "Exposure Scenario for CTUIR Traditional Subsistence Lifeways." (Department of Science and Engineering, Confederated Tribes of the Umatilla Indian Reservation: Pendleton, OR; 2004).

<sup>25</sup>B. Harper, *et al.* "Subsistence Exposure Scenarios for Tribal Applications." *Human and Ecological Risk Assessment* 18 (2012): 810–831.

<sup>26</sup>B.L. Harper, *et al.* *Traditional Tribal Subsistence Exposure Scenario and Risk Assessment Guidance Manual*. EPA-Star-J1-R831046. Corvallis, OR: Oregon State University; 2007.

<sup>27</sup>J.L. Donatuto, T.A. Satterfield, and R. Gregory. "Poisoning the Body to Nourish the Soul: Prioritising Health Risks and Impacts in a Native American Community." *Health, Risk & Society* 13 (2011): 103–127.

<sup>28</sup>United States Environmental Protection Agency. (Paper on Tribal Issues Related to Tribal Traditional Lifeways, Risk Assessment, and Health & Well Being: Documenting What We've Heard, National EPA-Tribal Science Council, #530D06001: Washington, DC; 2006).

<sup>29</sup>S.G. Harris and B.L. Harper. "Using Eco-Cultural Dependency Webs in Risk Assessment and Characterization of Risks to Tribal Health and Cultures." *Environmental Science and Pollution Research Special Issue(2)* (2000): 91–100.

<sup>30</sup>B. Harper, *et al.* "Subsistence Exposure Scenarios for Tribal Applications." *Human and Ecological Risk Assessment* 18 (2012): 810–831.

<sup>31</sup>J. Donatuto and B.L. Harper. "Issues in Evaluating Fish Consumption Rates for Native American Tribes." *Risk Analysis* 28 (2008): 1497–1506.

<sup>32</sup>S.G. Harris and B.L. Harper. "Using Eco-Cultural Dependency Webs in Risk Assessment and Characterization of Risks to Tribal Health and Cultures." *Special Issue(2)* (2000): 91–100.

<sup>33</sup>S.G. Harris and B.L. Harper. "A Native American Exposure Scenario." *Risk Analysis* 17 (1997): 789–795.

<sup>34</sup>Columbia River Inter-Tribal Fish Commission. *A Fish Consumption Survey of the Umatilla, Nez Perce, Yakama and Warm Springs Tribes of the Columbia River Basin*. Portland, OR; 1994, Technical Report 94-3.

<sup>35</sup>U.S. Environmental Protection Agency—Region 10. Technical Support Document for Action on the State of Oregon's New and Revised Human Health Water Quality Criteria for Toxics and Associated Implementation Provisions Submitted July 12 and 21, 2011. 2011.

<sup>36</sup>A. Matzke, D. Sturdevant, and J. Wigal. *Human Health Criteria Issue Paper: Toxics Rulemaking 2008–2011*. (Oregon Department of Environmental Quality; Oregon; 2011).

<sup>37</sup>S.G. Harris and B.L. Harper. "Exposure Scenario for CTUIR Traditional Subsistence Lifeways." (Department of Science and Engineering, Confederated Tribes of the Umatilla Indian Reservation: Pendleton, OR; 2004).

<sup>38</sup>B.L. Harper, *et al.* *Traditional Tribal Subsistence Exposure Scenario and Risk Assessment Guidance Manual*. EPA-Star-J1-R831046. Corvallis, OR: Oregon State University; 2007.

<sup>39</sup>J. Donatuto and B.L. Harper. "Issues in Evaluating Fish Consumption Rates for Native American Tribes." *Risk Analysis* 28 (2008): 1497–1506.

<sup>40</sup>J.L. Donatuto, T.A. Satterfield, and R. Gregory. "Poisoning the Body to Nourish the Soul: Prioritising Health Risks and Impacts in a Native American Community." *Health, Risk & Society* 13 (2011): 103–127.

<sup>41</sup>P. Nadasdy. "The Politics of TEK: Power and the 'Integration' of Knowledge." *Arctic Anthropology* 36 (1999) (1/2): 1–18.

<sup>42</sup>N.D. Forsberg, G.R. Wilson, and K.A. Anderson. "Determination of Parent and Substituted Polycyclic Aromatic Hydrocarbons in High-Fat Salmon Using a Modified QuEChERS Extraction, Dispersive SPE and GC-MS." *Journal of Agricultural Food and Chemistry* 59 (2011): 8108–8116.

<sup>43</sup>O. Motorykin, *et al.* "Determination of Parent and Hydroxy PAHs in Personal PM(2.5) and Urine Samples Collected During Native American Fish Smoking Activities." *Science of Total Environment* 505 (2015): 694–703.

TABLE 1. TIMELINE OF CTUIR-OSU PARTNERSHIP AND PRODUCTS

Date	Event
2003	<i>Awarded:</i> EPA-STAR Grant—JI-R831046 (2003–2007) Regional tribal exposure scenarios based on major ecological zones and traditional subsistence lifestyles
2006	Memorandum of understanding between OSU and CTUIR/DOSE signed
2008	<i>Publication:</i> B.L. Harper, <i>et al.</i> “Traditional Tribal Subsistence Exposure Scenario and Risk Assessment Guidance Manual.” EPA-Star-JI-R831046. Corvallis, OR: Oregon State University; 2007.
2009	<i>Awarded:</i> NIEHS Superfund Research Program—P42ESO16465; Tribal-university evaluation of chemical exposures to improve community health, PAHs: New technologies and emerging health risks
2010	<i>Project:</i> Ambient air quality study <i>Project:</i> Smoked Salmon Inhalation study (air and urine samples collected)
2011	<i>Publication:</i> N.D. Forsberg, G.R. Wilson, and K.A. Anderson. “Determination of Parent and Substituted Polycyclic Aromatic Hydrocarbons in High-Fat Salmon Using a Modified QuEChERS Extraction, Dispersive SPE and GC-MS.” <i>Journal of Agricultural and Food Chemistry</i> 59(15) (2011): 8108–8116. <i>Publication:</i> A. Harding, <i>et al.</i> “Conducting Research with Tribal Communities: Sovereignty, Ethics and Data-Sharing Issues.” <i>Environmental Health Perspectives</i> 120 (Sep 2011): 11–24. <i>Outreach:</i> Personal air monitor training video created. < <a href="http://superfund.oregonstate.edu/main_news">http://superfund.oregonstate.edu/main_news</a> > <i>Outreach:</i> CTUIR-OSU Partnership Newsletter
2012	<i>Project:</i> (Passive sampler device) PSD deployed in Nixya’awii Governance Center <i>Project:</i> Evaluation of PAH in traditionally prepared salmon <i>Publication:</i> B. Harper, <i>et al.</i> “Subsistence Exposure Scenarios for Tribal Applications.” <i>Human and Ecological Risk Assessment</i> 18 (2012): 810–831. <i>Publication:</i> N.D. Forsberg, <i>et al.</i> “Effect of Native American Fish Smoking Methods on Dietary Exposure to Polycyclic Aromatic Hydrocarbons and Possible Risks to Human Health.” <i>Journal of Agricultural and Food Chemistry</i> 60 (2012): 6899–6906. <i>Outreach:</i> CTUIR-OSU Partnership Newsletter
2013	<i>Publication:</i> M.B. Schure, <i>et al.</i> “Perceptions of the Environment and Health Among Members of the Confederated Tribes of the Umatilla Indian Reservation.” <i>Environmental Justice</i> 6 (2013): 115–120.
2014	<i>Renewed:</i> NIEHS Superfund Research Program—P42ESO16465 <i>Project:</i> Smoked Salmon Ingestion study <i>Outreach:</i> CTUIR-OSU Partnership Newsletter
2015	<i>Publication:</i> O. Motorykin, <i>et al.</i> “Determination of Parent and Hydroxy PAHs in Personal PM <sub>2.5</sub> and Urine Samples Collected During Native American Fish Smoking Activities.” <i>Science of the Total Environment</i> 505 (2015): 694–703. <i>Publication:</i> O. Motorykin, <i>et al.</i> “Metabolism and Excretion Rates of Parent and Hydroxy-PAHs in Urine Collected After Consumption of Traditionally Smoked Salmon for Native American Volunteers.” <i>Science of the Total Environment</i> 514 (2015): 170–177. <i>Publication:</i> S. Lafontaine, <i>et al.</i> “Relative Influence of Trans-Pacific and Regional Atmospheric Transport of PAHs in the Pacific Northwest, U.S.” <i>Environmental Science and Technology</i> (2015). <i>Project:</i> Smoked salmon reports returned

CTUIR, Confederated Tribes of the Umatilla Indian Reservation; EPA, U.S. Environmental Protection Agency; OSU, Oregon State University; PAH, polycyclic aromatic hydrocarbon; STAR, Science to Achieve Results.

(30–40×) than those found in commercial cold smoked salmon.<sup>44</sup> However, very little is known about the absorption, metabolism, and excretion of the different PAHs found in the traditionally smoked salmon. A secondary study was designed to collect information that would begin to address concerns raised by Tribal members. All aspects of the study were jointly designed by the research teams at CTUIR-DOSE and OSU-SRP. Considerations for reporting and sharing data were enumerated in the MDSA that has been the

foundation of the CTUIR-OSU partnership. This research was approved by the OSU Institutional Review Board, the Northwest Portland Area Indian Health Board Institutional Review Board, and the CTUIR Health Commission.

As previously described,<sup>45</sup> DOSE recruited nine adult non-smoking CTUIR tribal members through convenience techniques, using word of mouth. The language to describe the study was drafted in collaboration between DOSE and OSU:

<sup>44</sup>N.D. Forsberg, *et al.* “Effect of Native American Fish Smoking Methods on dietary Exposure to Polycyclic aromatic Hydrocarbons and Possible Risks to Human Health.” *Journal of Agricultural and Food Chemistry* 60 (2012): 6899–6906.

<sup>45</sup>O. Motorykin, *et al.* “Metabolism and Excretion Rates of Parent and Hydroxy-PAHs in Urine Collected After Consumption of Traditionally Smoked Salmon for Native American Volunteers.” *Science of the Total Environment* 514 (2015): 170–177.

The Department of Science and Engineering (DOSE) has partnered with the Superfund Research Program (SRP) at Oregon State University to measure how our bodies eliminate residues that can attach to food when it is smoked. This study will focus on residues called polycyclic aromatic hydrocarbons (PAHs), which are produced by burning wood and other materials. This study will identify those residues, and how much of these residues are absorbed in the body....Participants will be asked to eat traditionally smoked salmon and provide urine samples to help researchers understand how the residues produced during smoking events are processed by the body.

Participants were enrolled and provided informed consent at a 1-hour meeting hosted by DOSE and OSU researchers. At the meeting, participants received an informational handout and letter detailing the study. All participants were asked to maintain a low-PAH diet 48 hours before beginning the study. A low-PAH lunch was served<sup>46</sup> and meals were provided while the scientific and cultural importance of the research was discussed. An OSU project coordinator explained the MDSA and explained that all samples and data belonged to CTUIR.

Following informed consent, participants then completed a survey to evaluate nondietary PAH exposures. Two days after the enrollment meeting, participants arrived at a tribally owned restaurant and provided a baseline urine sample, as previously described.<sup>47</sup> Each participant consumed 50 g of traditionally smoked salmon and provided four additional urine samples over the next 24 hours. A DOSE technician collected the samples and provided each participant with a \$25 gift card. Samples were returned to OSU for analysis. Analytical chemists at OSU designed an improved method for measuring urinary PAHs for this project and all samples were analyzed for 19 PAHs and 33 hydroxylated-PAHs (OH-PAHs), the metabolism product of PAHs.<sup>48,49</sup>

### DISCLOSING DATA TO A TRIBAL COMMUNITY

While it was originally planned to share aggregated data with the community, the participants specifically requested to see their data in addition to aggregated data. Considerable research supports disclosure of biomedical

data to participants. The very nature of CBPR can support data disclosure,<sup>50</sup> as do the ethical principles of clinical medicine<sup>51,52</sup> and the ability to improve education on the research.<sup>53,54</sup> There are associated risks, such as participants feeling their expectations were not met or participants feeling concern/fear when they receive their results. In addition, even when interventions are possible, participants may not have the ability to make changes to reduce their risk. However, these risks must be balanced with the benefits and expectations of the study.

In this study, we describe the process, by which data were compiled and disclosed to participants and how published best practices were modified for use within a tribal community. Reports were designed to combine graphs and text with data placed in the context of the study population and accompanied by annotated graphical legends.<sup>55</sup>

Many report-back styles focus on the individual exposure, whereas tribal communities prefer that research and data are discussed within the context of the community.<sup>56</sup> In addition, the novelty of this study limited options for appropriate comparison groups. Following analysis and scientific peer review of the results,<sup>57</sup> the data were used to create relevant reports that interpreted the toxicological and biological results within the cultural framework of CTUIR members. This meant that reports described the benefits of salmon consumption, the recognition of salmon as a culturally important species to CTUIR, and highlighted the main findings from the study rather than conclusions specific to the individual's data. The report was created through an iterative process between public health, chemists, epidemiologists, toxicologists, and community engagement specialists.

<sup>50</sup>R. Morello-Frosch, *et al.* "Toxic Ignorance and Right-to-Know in Biomonitoring Results Communication: A Survey of Scientists and Study Participants." *Environmental Health* 8 (2009): 6.

<sup>51</sup>J.G. Brody, *et al.* "Improving Disclosure and Consent: 'Is It Safe?': New Ethics for Reporting Personal Exposures to Environmental Chemicals." *American Journal of Public Health* 97 (2007): 1547–1554.

<sup>52</sup>J.W. Nelson, *et al.* "A New Spin on Research Translation: The Boston Consensus Conference on Human Biomonitoring." *Environmental Health Perspectives* 117 (2009): 495–499.

<sup>53</sup>S. Finn and L. O'Fallon. "The Emergence of Environmental Health Literacy-From Its Roots to Its Future Potential." *Environmental Health Perspectives* (2015). DOI: 10.1289/ehp.1409337.

<sup>54</sup>L.R. O'Fallon and A. Deary. "Community-Based Participatory Research as a Tool to Advance Environmental Health Sciences." *Environmental Health Perspectives* 110 (suppl 2) (2002): 155–159.

<sup>55</sup>S.C. Dunagan, *et al.* *When Pollution is Personal: Handbook for Reporting Results to Participants in Biomonitoring and Personal Exposure Studies.* (Newton, MA: Silent Spring Institute, 2013).

<sup>56</sup>S. Wilhelm, *et al.* "Lessons Learned Conducting Breastfeeding Intervention Research in Two Northern Plains Tribal Communities." *Breastfeeding Medicine* 7 (2012): 167–172.

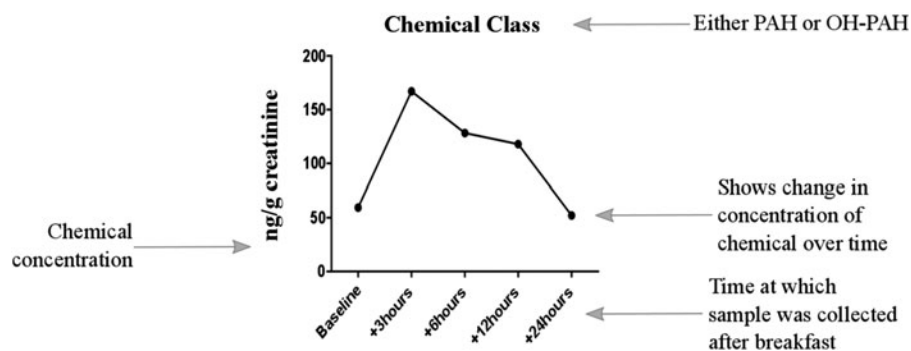
<sup>57</sup>O. Motorykin, *et al.* "Metabolism and Excretion Rates of Parent and Hydroxy-PAHs in Urine Collected after Consumption of Traditionally Smoked Salmon for Native American Volunteers." *Science of the Total Environment* 514 (2015): 170–177.

<sup>46</sup>Z. Li, *et al.* "Excretion Profiles and Half-Lives of Ten Urinary Polycyclic Aromatic Hydrocarbon Metabolites after Dietary Exposure." *Chemical Research in Toxicology* 25 (2012): 1452–1461.

<sup>47</sup>O. Motorykin, *et al.* "Metabolism and Excretion Rates of Parent and Hydroxy-PAHs in Urine Collected After Consumption of Traditionally Smoked Salmon for Native American Volunteers." *Science of the Total Environment* 514 (2015): 170–177.

<sup>48</sup>O. Motorykin, *et al.* "Determination of Parent and Hydroxy PAHs in Personal PM<sub>2.5</sub> and Urine Samples Collected During Native American fish Smoking Activities." *Science of Total Environment* 505 (2015): 694–703.

<sup>49</sup>O. Motorykin, *et al.* "Metabolism and Excretion Rates of Parent and Hydroxy-PAHs in Urine Collected After Consumption of Traditionally Smoked Salmon for Native American Volunteers." *Science of the Total Environment* 514 (2015): 170–177.



**FIG. 1.** A graphical legend was provided to illustrate how the data were graphed and to aid interpretation of results.

The data disclosure was prefaced by a cover letter, which stated the study rationale and the cultural context for the research. Also included was a previously published newsletter, which also described the rationale for the metabolism study and background information on the partnership and previous research studies. The cover letter read:

By eating a single small serving of traditionally smoked salmon of 50 grams, and providing five urine samples over a 24-hour period, you provided data that helps us to learn how people absorb and eliminate polycyclic aromatic hydrocarbons (PAHs). We know that people are exposed to PAHs when they eat traditionally smoked salmon. During the smoking process, PAHs are emitted from the wood burning fire and are absorbed by the fish. People can metabolize PAHs. This process occurs in the liver where enzymes add an oxygen molecule to their chemical structure. These PAH metabolites are called hydroxylated PAHs, which are abbreviated to OH-PAHs. OH-PAHs are more soluble than PAHs, which means they dissolve more easily in liquids. This helps our bodies eliminate PAHs in urine and feces.

The second page provided bulleted conclusions from the study, which directed the reader to the page with the relevant data:

- After eating 50 g of traditionally smoked salmon, the amount of PAHs in urine increased. This indicates that even small amounts of PAHs that are present in the smoked salmon are being absorbed by the body.
- The absorbed PAHs were quickly metabolized to improve their excretion in urine. As seen on page 3, the concentration of PAH metabolites (OH-PAHs) peaked at ~3 hours and the concentration of un-metabolized PAHs peaked at 6 hours.
- Depending on the individual, the peak levels of PAHs and OH-PAHs occurred at different times. This indicates that metabolism of PAHs is complicated and involves many biological processes, which likely differ between individuals.
- After 24 hours, the concentration of PAHs and their metabolites returned almost to baseline levels. This indicates that the body was able to eliminate almost all of the PAHs it absorbed from the 50 g of traditionally smoked salmon within one day.
- Participants who drank more water had faster elimination of PAHs and their metabolites in their urine.

This suggests that people should drink more water when eating traditionally smoked foods to improve elimination of PAHs in urine.

- Salmon is a nutritious food. To continue enjoying the health benefits and the cultural heritage associated with salmon, while also limiting exposure to PAHs, we recommend that people rotate eating fresh, frozen, canned, and dried salmon with smoked salmon. Children and pregnant women may also want to limit how much smoked salmon they eat and enjoy salmon prepared in other ways.

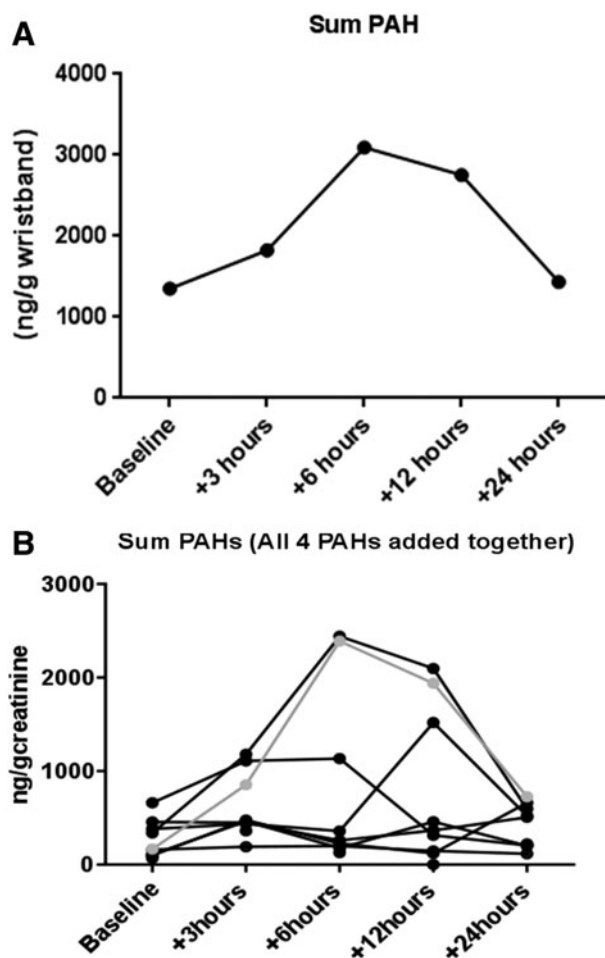
While the report highlighted key findings, results were not presented in terms of human health risk, although many data disclosure mechanisms use this as a way to provide context for the data.<sup>58</sup> Instead, the focus was to help participants understand the results and to highlight suggestions for reducing potential risk. This is an approach previously used with pesticide risk assessments.<sup>59</sup> The study was not designed to evaluate human health given the small sample size ( $n=9$ ), but rather to evaluate the absorption, metabolism, and excretion of PAHs following ingestion. For these reasons, the chemical concentrations of each individual PAH or OH-PAH were not included, but were available to participants upon request.

A graphical legend designed to build graph literacy and enhance understanding of the data accompanied all data presentations (Fig. 1). Aggregate data from the study were presented in two forms. The first graph showed the average PAH and OH-PAH concentrations in urine over time (Fig. 2A). The second graph showed the data from all nine participants, with the individual's data highlighted (Fig. 2B). Descriptive text accompanied the data:

The top graph is a template, explaining how the graph is designed for the PAH and OH-PAH sums. Next, we show the average response for all nine individuals for total

<sup>58</sup>S.C. Dunagan, *et al.* *When Pollution is Personal: Handbook for Reporting Results to Participants in Biomonitoring and Personal Exposure Studies*. (Newton, MA: Silent Spring Institute, 2013).

<sup>59</sup>S.A. Quandt, *et al.* "Reporting Pesticide Assessment Results to Farmworker Families: Development, Implementation, and Evaluation of a Risk Communication Strategy." *Environmental Health Perspectives* 112 (2004): 636.



**FIG. 2.** Example of how aggregate results were presented. (A) Example graph showing sum PAH concentration over the 24-hour study period. Sum OH-PAHs were also presented in the same format. (B) The grey line depicts the individual's results; the black lines represent the results of the other eight participants. Sum OH-PAHs were presented in the same format. PAH, polycyclic aromatic hydrocarbon.

PAH and total OH-PAH at each of the five time points. This information shows us how average PAH and OH-PAH chemical concentrations changed over time for this group of people.

Your individual results are shown in grey and the results from the other participants are shown in black. If you would like to see your individual results for each chemical measured, please contact us. These graphs show how people have slightly different PAH absorption, metabolism, and excretion. Yet, despite these differences, everyone's PAH and OH-PAH levels return nearly to baseline levels within 24 hours.

Finally, basic information on PAHs was provided, along with the rationale used by DOSE to evaluate exposures to PAHs:

The DOSE and other scientists consider several factors when determining the potential for PAHs to impact people's health. These include the following:

- Identifying and measuring specific PAH compounds in air, water, soil, and food.
- Measuring the amount of contact a person has with specific PAH compounds in their environment and diet.
- Learning about the toxicity of each PAH compound.

Reports were returned to participants and contact information for the OSU coordinator was provided.

#### Summary of data disclosure recommendations

A comprehensive handbook details many best practices in reporting data, including placing participant levels in context to national averages, supplying individualized recommendations to each study participant, and providing suggested alternatives to reduce exposure.<sup>60</sup> These were three recommendations that were specifically altered when preparing the CTUIR reports.

Provide appropriate context for the results. The first peer-reviewed publication that reported the concentration of PAHs in the urine of people who smoked salmon did include a comparison to the National Health and Nutrition Examination Survey (NHANES),<sup>61</sup> but for the personal reports, it was deemed inappropriate, as the NHANES data are neither reflective of the unique exposures sustained by Tribal populations nor are they reflective of purposeful dietary challenges, that is, sampling following ingestion of smoked salmon.<sup>62,63,64,65</sup> The results were, therefore, presented within the context of the study population.

Use a community, not individual, context. Individual results were not tabulated or presented in descriptive text to make any conclusions about the individual's sample. The goal of the report was to present data within a community framework, rather than an individual framework and focusing on the individual's sample detracted from that viewpoint.

Recognize the cultural framework. When working with tribally important foods, the significance of the data

<sup>60</sup>S.C. Dunagan, et al. *When Pollution is Personal: Handbook for Reporting Results to Participants in Biomonitoring and Personal Exposure Studies*. (Newton, MA: Silent Spring Institute, 2013).

<sup>61</sup>O. Motorykin, et al. "Metabolism and Excretion Rates of Parent and Hydroxy-PAHs in Urine Collected After Consumption of Traditionally Smoked Salmon for Native American Volunteers." *Science of the Total Environment* 514 (2015): 170–177.

<sup>62</sup>S.G. Harris and B.L. Harper. "A Native American Exposure Scenario." *Risk Analysis* 17 (1997): 789–795.

<sup>63</sup>S.G. Harris and B.L. Harper. "Exposure Scenario for CTUIR Traditional Subsistence Lifeways." (Department of Science and Engineering, Confederated Tribes of the Umatilla Indian Reservation: Pendleton, OR; 2004).

<sup>64</sup>B. Harper, et al. "Subsistence Exposure Scenarios for Tribal Applications." *Human and Ecological Risk Assessment* 18 (2012): 810–831.

<sup>65</sup>B.L. Harper, et al. *Traditional Tribal Subsistence Exposure Scenario and Risk Assessment Guidance Manual*. EPA-Star-J1-R831046. Corvallis, OR: Oregon State University; 2007.

goes beyond that of a risk assessment. Data presentation and associated recommendations should account for the cultural significance of traditional foods for Native Americans, which goes beyond that of nutrition.<sup>66</sup> In this study, the focus of the report was on understanding the data and options for reducing exposure if a participant felt it was necessary.

### CONCLUSIONS

Sharing data from environmental studies that explore novel environmental health concerns within a specific cultural framework helps build scientific and cultural capacity in both Tribal and University partners. A MDSA and collaboration help create transparency and establish clear boundaries for all study parameters. Using the results from a novel dietary exposure study, we illustrated several best practices for sharing data with a Tribal community. The reports were designed to be respectful of the importance of salmon as both a nutritional and cultural element.

Most importantly, the data were reported back at the request of the study participants. This is an important el-

ement of CBPR and must be treated with the same rigor as that given to the data analysis. The field of data disclosure is relatively new, but when handled correctly can improve education within the community, reduce distrust, and enhance environmental health literacy.<sup>67,68</sup>

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### AUTHOR DISCLOSURE STATEMENT

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<sup>66</sup>J.L. Donatuto, T.A. Satterfield, and R. Gregory. "Poisoning the Body to Nourish the Soul: Prioritising Health Risks and Impacts in a Native American Community." *Health, Risk & Society* 13 (2011): 103–127.

<sup>67</sup>L.R. O'Fallon and A. Dearry. "Community-Based Participatory Research as a Tool to Advance Environmental Health Sciences." *Environmental Health Perspectives* 110 (suppl 2) (2002): 155–159.

<sup>68</sup>J.W. Nelson, *et al.* "A New Spin on Research Translation: the Boston Consensus Conference on Human Biomonitoring." *Environmental Health Perspectives* 117 (2009): 495–499.