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# INTELLECTUAL PROPERTY RIGHTS AND INFORMED CONSENT IN AMERICAN INDIAN COMMUNITIES: LEGAL AND ETHICAL ISSUES

Naomi Palosaari\*

## Introduction

Linguistic and anthropological research can provide great benefits to native communities in the form of documentation of cultural practices and resources for language preservation and language teaching. But such research can also pose risks of harm, both to social and community structure and in the ways that the research results can be used.<sup>1</sup> Particular harms can result from use of research data, such as the danger that (1) research can be used in ways antithetical to tribal values, (2) private, sacred knowledge can be published and exposed to the outside world against a tribe's wishes, or (3) traditional knowledge can be appropriated by persons unconnected with a tribe and used for commercial or personal purposes in ways that are antithetical to tribal values.<sup>2</sup> Some indigenous groups may experience emotional harm as a result of the diffusion of their culture.<sup>3</sup>

This comment focuses on two related issues in research involving traditional knowledge: informed consent and intellectual property rights. Part I describes the special context of research on traditional knowledge, with particular emphasis on language documentation research and native

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1. See CLAIRE BOWERN, LINGUISTIC FIELDWORK 178-79 (2009) (describing possible harms that can result to the language community from linguistic fieldwork); Arienne M. Dwyer, *Ethics and Practicalities of Cooperative Fieldwork and Analysis*, in ESSENTIALS OF LANGUAGE DOCUMENTATION 31, 38 (Jost Gippert, Nikolaus P. Himmelmann & Ulrike Mosel eds., 2006) (describing inadvertent harm that can result from language documentation research). See generally Keren Rice, *Ethical Issues in Linguistic Fieldwork*, in THE OXFORD HANDBOOK OF LINGUISTIC FIELDWORK 407, 408 (Nicholas Thieberger ed., 2012) (identifying potential ethical issues for the novice fieldworker).

2. See, e.g., MICHAEL F. BROWN, WHO OWNS NATIVE CULTURE? 5-6 (2003); JAMES A. R. NAFZIGER ET AL., CULTURAL LAW: INTERNATIONAL, COMPARATIVE, AND INDIGENOUS 629-30 (2010).

3. BROWN, *supra* note 2, at 6.

peoples in the United States. Part II describes particular issues with existing intellectual property protections in the United States in relation to traditional knowledge. Part III discusses the legal and ethical framework for informed consent practices in relation to research on traditional knowledge. Part IV proposes an approach to principled data collection for research on traditional knowledge and describes an ethical framework for fully delineated informed consent, arguing that consent cannot be fully informed unless it includes clarification of the ownership and usage rights of the data to be collected.

### *I. Research in Indian Country*

#### *A. Cultural Context*

Indigenous groups in North America have a turbulent history with western researchers. Many tribes view research efforts with skepticism, having been the subject of much prior research with little knowledge of the outcome of research studies or the use to which their data has been put.<sup>4</sup> Many share a common feeling of mistrust towards outside researchers. One reason for mistrust is the failure of researchers to share the results of their research with the communities they research. For example, author Diana Campbell describes this common scenario in the context of research on traditional Alaskan knowledge:

It hasn't always been a mutually beneficial relationship between informants and researchers. A story I've heard many times is how scientists go into a community, conduct their study and leave, never to return. They go on to earn doctoral or master's degrees, publish their findings in scholarly journals and build careers. The people left behind have no idea what's been said about them, and their lives aren't bettered by the visit.<sup>5</sup>

Unfortunately, examples abound of researchers abusing the trust of native groups through unethical research methods, misappropriation, or

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4. See, e.g., CANADIAN INSTS. OF HEALTH RESEARCH, NAT. SCIS. & ENG'G RESEARCH COUNCIL OF CANADA & SOC. SCIS. & HUMANITIES RESEARCH COUNCIL OF CANADA, TRI-COUNCIL POLICY STATEMENT: ETHICAL CONDUCT FOR RESEARCH INVOLVING HUMANS 105 (2010), [http://www.pre.ethics.gc.ca/pdf/eng/tcps2/TCPS\\_2\\_FINAL\\_Web.pdf](http://www.pre.ethics.gc.ca/pdf/eng/tcps2/TCPS_2_FINAL_Web.pdf) [hereinafter CANADIAN RESEARCH GUIDELINES].

5. Diana Campbell, *Scientists Relying More on Traditional Alaska Native Knowledge*, ALASKA DISPATCH NEWS (Sept. 27, 2015), <http://www.adn.com/article/20150927/scientists-relying-more-traditional-alaska-native-knowledge>.

publication of cultural material that the group considers private. One notorious example is the publication of Hopi religious materials by H.R. Voth in the early twentieth century.<sup>6</sup> Voth was a missionary who began research on the Hopi religion to learn about “the beliefs he was trying to supplant.”<sup>7</sup> Voth gained access to private Hopi ceremonies: there are conflicting accounts that some Hopi priests invited Voth to private religious ceremonies while other Hopi reported being “afraid of him” and that he forced his way into sacred rituals.<sup>8</sup> Voth profited financially from his studies; for instance, he was hired to create displays related to Hopi religious practices for museums and tourist sites and was offered a position at the Chicago Field Museum of Natural History.<sup>9</sup> Voth’s publication of photographs of religious rituals and detailed written descriptions of Hopi ritual practices resulted in the broad dissemination of knowledge that the Hopi considered privileged, offending the sensibilities of many Hopi people.<sup>10</sup> Many Native Americans share the concern that dissemination of sacred aspects of traditional cultures causes those aspects to lose meaning, resulting in cultural harm.<sup>11</sup>

Even when researchers observe proper procedures in data collection, they have not always complied with ethical practices in using the resulting data.<sup>12</sup> For example, in a more recent case, Havasupai tribal members filed suit against Arizona State University because blood samples that had been collected for diabetes testing were used for other genetic research without obtaining the research participants’ consent for such use.<sup>13</sup> Tribal members claimed that the researchers betrayed their trust and violated the research agreement, and that the researchers’ actions violated their “privacy rights as well as their cultural, religious, and legal rights.”<sup>14</sup> The lawsuit was settled with a \$700,000 payment to the tribal members and the return of

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6. See BOWERN, *supra* note 1, at 11.

7. *Id.* at 12.

8. *Id.* at 13 (quoting DON C. TALAYESVA, *SUN CHIEF: AUTOBIOGRAPHY OF A HOPI INDIAN* 252 (Leo W. Simmons ed., 1942)).

9. BROWN, *supra* note 2, at 12.

10. *Id.* at 13.

11. See Stephen D. Osborne, Special Feature, *Protecting Tribal Stories: The Perils of Propertization*, 28 AM. INDIAN L. REV. 203, 205 (2003-2004).

12. See generally *Havasupai Tribe of Havasupai Reservation v. Ariz. Bd. of Regents*, 204 P.3d 1063 (Ariz. Ct. App. 2008).

13. *Id.* at 1075.

14. *Id.* at 1077.

the blood samples and all associated research materials.<sup>15</sup> In this case, the protections that should have been imposed by informed consent practices were inadequate to prevent uses of data that the tribal members considered inappropriate. In the wake of *Havasupai*, there were calls for researchers working with Native groups to improve their cultural competency in and informed consent procedures.<sup>16</sup> With respect to research on traditional knowledge, both researchers and the indigenous communities being researched have expressed similar concerns and demanded increased collaboration with indigenous communities in determining the direction and outcomes of research.<sup>17</sup> For example, Professor Andrew Turk considers it imperative that the ethics of ethnogeographical research include the “maximum possible community control of the project” and that researchers obtain approval from language community representatives for the publication of collected data as well as culturally-appropriate acknowledgement of participants.<sup>18</sup>

#### *B. Documentary Research Paradigm*

In the face of increasing globalization, cultures and languages are rapidly becoming forgotten or lost. Scholars worldwide have expressed concern about the massive loss of scientific knowledge that will accompany the losses of language and culture.<sup>19</sup> In 1992, linguistics experts publicly raised concerns about an impending situation of language loss, estimating that over half of the world’s languages were likely to be lost within the next 100 years.<sup>20</sup> This global loss of language also threatens American Indian

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15. Charles Pensabene, *A Canyon Full of Woes: The Havasupai Tribe Illustrates the Need for Cultural Competency in Genetic Research*, 7 ALB. GOV'T L. REV. 637, 642 (2014).

16. *Id.* at 655; Nathalie Piquemal, *Free and Informed Consent in Research Involving Native American Communities*, AM. INDIAN CULTURE & RES. J., vol. 25, no. 1 (2001), at 65, 69.

17. See Andrew G. Turk et al., *Geography: Documenting Terms for Landscape Features*, in THE OXFORD HANDBOOK OF LINGUISTIC FIELDWORK, *supra* note 1, at 368, 389 (describing reasons for indigenous resistance to outside researchers and the comments of indigenous participants in a language mapping workshop).

18. *Id.* at 390.

19. See, e.g., Anthony C. Woodbury, *What Is an Endangered Language?*, LINGUISTIC SOC'Y OF AM., <http://www.linguisticsociety.org/content/what-endangered-language> (last visited Nov. 29, 2016); WADE DAVIS, LIGHT AT THE EDGE OF THE WORLD: A JOURNEY THROUGH THE REALM OF VANISHING CULTURES 5-7 (2007); ENDANGERED LANGUAGES: LANGUAGE LOSS AND COMMUNITY RESPONSE (Lenore A. Grenoble & Lindsay J. Whaley eds., 1998); Christopher Moseley, *Introduction to ATLAS OF THE WORLD'S LANGUAGES IN DANGER* 8 (Christopher Moseley ed., 3d ed. 2010).

20. Michael Krauss, *The World's Languages in Crisis*, 68 LANGUAGE 4 (1992).

communities who face unprecedented loss of linguistic and cultural knowledge.<sup>21</sup> Two of the top five global endangered language “hotspots” (places with languages that, due to the high genetic diversity, high levels of endangerment, and low levels of documentation, are in perhaps the greatest danger of extinction) can be found in North America.<sup>22</sup>

In response, institutions and governments have dedicated funding and scholarly initiative to activities such as language documentation.<sup>23</sup> Indigenous communities whose languages and cultures are diminishing are also expressing increasing alarm at the impending loss of their own linguistic and cultural knowledge, and are undertaking various efforts to support documentation at a local level as well as in partnership with academic and governmental entities.<sup>24</sup> The result is an exploding industry in documentary research and the proliferation of various types of “documentation” in diverse media.<sup>25</sup> The goal of language documentation is to create a “lasting, multipurpose record of a language,” striving to include “as many and as varied records as practically feasible.”<sup>26</sup> The ideal documentation is not limited to the collection of oral histories or traditional stories but also involves “a range of techniques that straddle traditional humanities and scientific methodologies.”<sup>27</sup> Documentation is not limited to primary recordings but may include grammatical information, observations on the process of telling stories or speaking the language, translations and transcriptions, and observations of linguistic structures or analyses of linguistic patterns.<sup>28 29</sup> The complex nature of this type of research raises a

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21. Chris Rogers, Naomi Palosaari & Lyle Campbell, *United States of America*, in ATLAS OF THE WORLD’S LANGUAGES IN DANGER, *supra* note 19, at 108.

22. *Top 5 Language Hotspots*, GLOBAL LANGUAGE HOTSPOTS, <http://www.swarthmore.edu/SocSci/langhotspots/> (last visited Nov. 29, 2016).

23. For example, the National Science Foundation has established a permanent Documenting Endangered Languages Program that distributed more than \$4 million in grant funding in 2014. See *Documenting Endangered Languages (DEL)*, NAT’L SCI. FOUND., [http://www.nsf.gov/funding/pgm\\_summ.jsp?pims\\_id=12816](http://www.nsf.gov/funding/pgm_summ.jsp?pims_id=12816) (last visited Nov. 29, 2016).

24. See Leanne Hinton, *Language Revitalization in North America and the New Direction of Linguistics*, 18 TRANSFORMING ANTHROPOLOGY 35, 36 (2010).

25. See Nicholas Thieberger, *Introduction*, in THE OXFORD HANDBOOK OF LINGUISTIC FIELDWORK, *supra* note 1, at 1.

26. Nikolaus P. Himmelmann, *Language Documentation: What Is It and What Is It Good For?*, in ESSENTIALS OF LANGUAGE DOCUMENTATION, *supra* note 1, at 1-2.

27. Nicholas Thieberger & Andrea L. Berez, *Linguistic Data Management*, in THE OXFORD HANDBOOK OF LINGUISTIC FIELDWORK, *supra* note 1, at 90, 93.

28. See, e.g., Sophie Salffner, *A Guide to the Ikaan Language and Culture Documentation*, 9 LANGUAGE DOCUMENTATION & CONSERVATION 237, 241 (2015) (describing community involvement in a language documentation project and the resulting

multitude of questions about accessibility, ownership, and control of the research results, particularly when the documentation includes expressions of traditional knowledge and cultural practices.

### C. Traditional Knowledge

Broadly, Traditional Knowledge (TK) refers to the knowledge base of an indigenous group. The scope of TK is not without controversy, with disagreement on the definitions of “traditional” and “knowledge.”<sup>30</sup> Acknowledging the lack of an international consensus on a definition, the World Intellectual Property Organization (WIPO) defines TK as “knowledge, know-how, skills and practices that are developed, sustained and passed on from generation to generation within a community, often forming part of its cultural or spiritual identity.”<sup>31</sup> TK is significant and identifiable not through its content, but through its mode of transmission: the “traditional” aspect of TK is not dependent on the “antiquity” of the knowledge but on “the way it is acquired and used.”<sup>32</sup>

TK is often used generally to encompass both the content of knowledge and the expression of that knowledge through traditional cultural expressions (TCEs).<sup>33</sup> TCEs “may include music, dance, art, designs, names, signs and symbols, performances, ceremonies, architectural forms, handicrafts and narratives, or many other artistic or cultural expressions.”<sup>34</sup> TCEs are often considered “expressions of folklore,” and comprise part of the “identity and heritage of a traditional or indigenous community.”<sup>35</sup>

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archival deposit which included video recordings, audio recordings, annotation files, images, scans of consultants’ notes, ethnographic films, calendars, academic papers, exhibition photo panels, anthropological field notes, and a metadata database).

29. *Id.* at 248.

30. Veronica Gordon, Note, *Appropriation Without Representation? The Limited Role of Indigenous Groups in WIPO's Intergovernmental Committee on Intellectual Property and Genetic Resources, Traditional Knowledge, and Folklore*, 16 VAND. J. ENT. & TECH. L. 629, 633 (2014) (“Tensions exist because these terms implicate the historical, political, and cultural differences that persist between and within indigenous groups and the international community.”).

31. *Traditional Knowledge*, WORLD INTELL. PROP. ORG., <http://www.wipo.int/tk/en/tk/> (last visited Jan. 6, 2015).

32. CHIDI OGUAMANAM, INTERNATIONAL LAW AND INDIGENOUS KNOWLEDGE: INTELLECTUAL PROPERTY, PLANT BIODIVERSITY, AND TRADITIONAL MEDICINE 25 (2006).

33. *Traditional Knowledge*, *supra* note 31.

34. *Traditional Cultural Expressions*, WORLD INTELL. PROP. ORG., <http://www.wipo.int/tk/en/folklore/>.

35. *Id.*; see also INTELLECTUAL PROPERTY AND TRADITIONAL CULTURAL EXPRESSIONS IN A DIGITAL ENVIRONMENT at xi (Christoph Beat Graber & Mira Burri-Nenova eds., 2008).

Some scholars, however, delineate TK and TCEs as separate concepts, placing them both under a broad category of “intangible cultural heritage” which includes TK and cultural expressions,<sup>36</sup> limiting TK to describe the underlying knowledge “resulting from intellectual activity in a traditional context.”<sup>37</sup> The research ethics guidelines promulgated by the Canadian government approach TK broadly and refer to the manner in which the knowledge is expressed as part of TK itself:

Traditional knowledge is specific to place, usually transmitted orally, and rooted in the experience of multiple generations. It is determined by an Aboriginal community’s land, environment, region, culture and language. Traditional knowledge is usually described by Aboriginal peoples as holistic, involving body, mind, feelings and spirit. Knowledge may be expressed in symbols, arts, ceremonial and everyday practices, narratives and, especially, in relationships. The word tradition is not necessarily synonymous with old. Traditional knowledge is held collectively by all members of a community, although some members may have particular responsibility for its transmission. It includes preserved knowledge created by, and received from, past generations and innovations and new knowledge transmitted to subsequent generations.<sup>38</sup>

In common with other authorities, the Canadian research guidelines emphasize the dynamic aspect and collective nature of TK. One question that arises is whether language itself should be considered to fall within the scope of either TK or TCE, because these categories may be protected differently under the domestic laws of different countries. Indigenous languages are developed and transmitted over generations and are used to communicate the collective knowledge of a community, and thus the knowledge itself of a language could fairly be considered to fall within the scope of TK. Language, however, must be given verbal expression to exist; in fact, it is the mechanism usually used to communicate and pass on TK.

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36. See Peter K. Yu, *Cultural Relics, Intellectual Property, and Intangible Heritage*, 81 TEMP. L. REV. 433, 440 (2008) (describing the international framework for protecting intangible cultural heritage and including examples from UNESCO). *But see* NAFZIGER ET AL., *supra* note 2, at 615 (delineating intangible cultural heritage as elements that are “characteristically incorporeal” in nature and traditional knowledge as linked to cultural expressions).

37. *Traditional Knowledge*, *supra* note 31.

38. CANADIAN RESEARCH GUIDELINES, *supra* note 4, at 108-09 (emphasis added).



Although many expressions of language will fall within the scope of TCE, it is not necessarily the case that every utterance of an individual speaker should be considered a TCE. Consider the following scenarios:

Scenario one:<sup>39</sup> A researcher records an elder telling a traditional story using video and audio recorders. The researcher translates the story into English and completes a written transcription and translation. The story is traditionally told only in winter and recounts the experiences of several animal characters. The story has been told for many generations and is one of many stories that represent different aspects of traditional cultural values. The story is a complex narrative that illustrates several features unique to the narrative structure of the speaker's language and culture.

Scenario two:<sup>40</sup> A researcher asks an elder to describe some of his personal experiences in his native language. The speaker tells about how he got his first job as a teenager and about the first years of his marriage and career. The researcher makes audio and video recordings and then works with the speaker to translate the story.

Scenario three:<sup>41</sup> Following the principle of reciprocity in research practices,<sup>42</sup> a researcher has consulted with members of the language community who indicated that teaching materials would be useful. The researcher worked with language learning professionals to design templates for some booklets, using pictures that would appeal to children and deciding the content according to several principles of language learning, incorporating structural and vocabulary goals. The researcher worked with a speaker to translate the statements into the indigenous language and make audio recordings. The researcher transcribed the statements into the writing system of the indigenous language. The language learning team then

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39. This scenario is drawn from Barre Toelken, *The Yellowman Tapes, 1966-1997*, 111 J. AM. FOLKLORE 381, 381-83 (1998) (telling the research situation described by Barre Toelken).

40. This scenario is drawn from the author's personal experience in the common academic framework of dissertation research in the "field," collecting and analyzing language data on an indigenous language of Mexico to create a grammatical description of the language.

41. This scenario is drawn from the author's field research, as described in Kristen M. Lindahl, Naomi Palosaari Fox, Jelena Markovic, Zuzana Tomas & Raichle Farrelly, *A Collaborative Approach to Materials Design* (1st International Conference on Language Documentation & Conservation, Mar. 14, 2009) (audio recording available at SCHOLAR SPACE, <http://hdl.handle.net/10125/5089>).

42. See Dwyer, *supra* note 1, at 37 (describing "reciprocity" as an obligation of the field researcher to contribute knowledge or language work that the community needs to the language community as part of the researcher's work to document the language).

incorporated the work into the language learning materials, which would be used with local children in a classroom setting or in after-school classes.

These scenarios could be viewed on a spectrum. Although all three scenarios are based on the expression of an indigenous language, the content differs greatly. Scenario one clearly falls within the scope of TCE: it is a story that has been transmitted orally for generations and represents the collective cultural knowledge of a people. As such, it should receive the treatment and protection of a TCE, with due care for culturally-appropriate use in the researcher's products.

Conversely, in scenario three, the content of the language is conceived by the research team according to their professional experience and training. The speaker relies on knowledge of the language that he has received through traditional means, but the content does not represent the cultural traditions of his people. The recorded utterances in scenario three have little in common with TCEs and in most cases will not need the same care in data curation as the traditional tale from scenario one.

Scenario two lies between these two extremes: the content is created by the speaker and represents his individual experiences, but his experiences were created within the context of his group membership, were shaped by a common group identity, and were expressed in a shared language. The events and perspectives he expresses reflect the knowledge that was developed through generations. While this narration of his life experiences is not "folklore," and thus falls outside of the generally-understood scope of TCE, the narration may be considered part of the "identity or heritage" of his community, and thus has some features of TCE.

## *II. Intellectual Property Protections*

### *A. International Initiatives*

Clearly, native communities have a stake in research involving their cultural heritage. And protections for cultural heritage—both tangible and intangible—are increasing in the international community as a whole.<sup>43</sup> For example, the Convention for the Safeguarding of Intangible Cultural Heritage identifies the need to protect intangible cultural heritage, including "the practices, representations, expressions, knowledge, skills as well as the instruments, objects, artefacts and cultural spaces associated therewith that communities, groups and, in some cases, individuals recognize as part of

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43. See Yu, *supra* note 36, at 434.

their cultural heritage.”<sup>44</sup> Under the auspices of the United Nations, the WIPO Intergovernmental Committee on Intellectual Property and Genetic Resources, Traditional Knowledge and Folklore is working to build consensus and develop an international legal instrument to protect TK.<sup>45</sup> Other subject-specific international instruments have implemented express protections for TK. The Convention on Biological Diversity,<sup>46</sup> for example, is a binding international instrument that requires parties to respect and preserve TK and share benefits of intellectual property developed from the TK of indigenous groups.<sup>47</sup> Article 27 of the Trade-Related Aspects of Intellectual Property Rights Agreement also refers to alternatives for the protection of knowledge.<sup>48</sup> Knowledge itself, however, is not yet well protected under domestic laws.<sup>49</sup>

Numerous researchers have identified problems with the ability of the intellectual property (IP) regime to adequately protect cultural heritage.<sup>50</sup> The types of material collected in research on intangible cultural heritage pose particularly complex problems for the IP regime, especially in the areas of jurisdiction and copyright. IP laws are based on the rationale that they incentivize creation by providing rights of exclusion.<sup>51</sup> Some regimes, such as the framework prevalent in Europe, are organized around a concept of moral rights—the idea that a person should be able to control the way her work is used.<sup>52</sup> The IP regime in the United States is primarily designed around a framework of “commercial exploitation of the works and

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44. UNESCO Convention for the Safeguarding of the Intangible Cultural Heritage art. 2, Oct. 17, 2003, 2368 U.N.T.S. 3 (entered into force Apr. 20, 2006).

45. Gordon, *supra* note 30, at 631; *see also Traditional Knowledge, supra* note 31.

46. *See generally* United Nations Convention on Biological Diversity art. 8(j), Jun. 5, 1992, 1760 U.N.T.S. 79.

47. OGUAMANAM, *supra* note 32, at 4-5.

48. *Id.* at 8.

49. Gordon, *supra* note 30, at 630-31 (“Conventional intellectual property regimes do not currently protect traditional knowledge, which has ancient roots and is often informally and orally transmitted.”).

50. Yu, *supra* note 36, at 452 (“[B]oth developed and less-developed countries suffer from the lack of or inadequate protection [of cultural heritage.]”); *see also* Angela R. Riley, *Recovering Collectivity: Group Rights to Intellectual Property in Indigenous Communities*, 18 CARDOZO ARTS & ENT. L.J. 175 (2000); Osborne, *supra* note 11, at 203; Doris Estelle Long, *Traditional Knowledge and the Fight for the Public Domain*, 5 J. MARSHALL REV. INTELL. PROP. L. 617, 618 (2006).

51. Deepa Varadarajan, *A Trade Secret Approach to Protecting Traditional Knowledge*, 36 YALE J. INT’L L. 371, 373-74 (2011).

52. *See* Paul Newman, *Copyright and other Legal Concerns*, in THE OXFORD HANDBOOK OF LINGUISTIC FIELDWORK, *supra* note 1, at 430, 436-37.

knowledge . . . [and] the maintenance of their control.”<sup>53</sup> It is easy to discern that the former approach is more conducive than the latter in its ability to serve the needs of indigenous groups who seek to protect their cultural heritage from disclosure in inappropriate contexts as well as prevent misrepresentation of sacred stories, rituals, values, and customs. For example, the moral right of attribution for written or oral works is not legally protected under federal law in the United States, so a storyteller may not be able to enforce a requirement that the origin and background of a traditional story be included with future versions or reproductions.<sup>54</sup> In many situations, indigenous groups in the United States may need to seek out innovative methods of legal protection, if they are able to secure the protections they desire at all.

The situation is further complicated by the fact that many indigenous communities do not agree internally about whether and how their cultural aspects should be commercialized or made publicly available.<sup>55</sup> Some scholars, recognizing that IP law provides inadequate protection for TK,<sup>56</sup> have called for a *sui generis* approach, a suggestion under consideration by the WIPO.<sup>57</sup> This approach would create unique protections for TK, separate from other types of IP rights. Other scholars have suggested strengthening the right to cultural privacy as a mechanism for protection against appropriation of TK.<sup>58</sup>

## B. U.S. Intellectual Property Regime

### 1. Protection of Knowledge

The market economy framework that underpins IP rights is ill-suited to provide protections for indigenous groups seeking to shield intangible cultural heritage.<sup>59</sup> For example, a tribe's primary reason for seeking protection under patent law may be to protect its proprietary knowledge in relation to plants, animals, and ceremonies. However, patent protection (1)

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53. Yu, *supra* note 36, at 447.

54. See, e.g., Stuart Schüssel, Note, *Copyright Protection's Challenges and Alaska Natives' Cultural Property*, 29 ALASKA L. REV. 313, 320 (2012) (describing the limitations on moral rights under U.S. law).

55. Osborne, *supra* note 11, at 205-06.

56. Dwyer, *supra* note 1, at 46. See generally J. Janewa OseiTutu, *A Sui Generis Regime for Traditional Knowledge: The Cultural Divide in Intellectual Property Law*, 15 MARQ. INTELL. PROP. L. REV. 147 (2011).

57. See Gordon, *supra* note 30, at 641; see also *Traditional Knowledge*, *supra* note 31.

58. See BROWN, *supra* note 2, at 27.

59. See OGUAMANAM, *supra* note 32, at 8.

is not universal, but country-specific, (2) requires disclosure, and (3) provides protection for a limited time,<sup>60</sup> which undercuts the value of its application in this situation.

In the alternative, some scholars have suggested that a tribe might seek trade secret protection for TK.<sup>61</sup> Trade secret protection does not require disclosure or proof of the novelty of a work, two of the obstacles that patent protection poses for TK, but measures to preserve secrecy must be demonstrated.<sup>62</sup> This raises questions about the measures tribes must take to maintain secrecy. Can a ceremony or medicinal composition that is commonly known to the members of the group, with a general understanding of secrecy but which the group has never explicitly agreed to protect in a certain way, still qualify for protection as a trade secret? What recourse does the group have if a secret is disclosed? And since the subject matter most relevant for this type of protection does not relate to a business process and may not provide a competitive advantage, can trade secret protection in its current form even be applied to TK?

A tribe seeking protection of cultural property from appropriation and misrepresentation may find some protection in trademark law under the Lanham Act and the Indian Arts and Crafts Act (IACA).<sup>63</sup> For example, the New Mexico District Court recently held that the Navajo Nation had standing to assert a claim against Urban Outfitters for the company's use of "Navajo" and other tribal names in its products and advertising.<sup>64</sup> The Lanham Act provides protection for trademark infringement, and the IACA gives tribes a distinct cause of action for any false suggestion that a product has an American Indian source.<sup>65</sup> But, like patents and trade secrets, trademark law is primarily aimed at protection of commercial interests and provides little remedy for noncommercial interests.

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60. Varadarajan, *supra* note 51, at 375; Richard A. Guest, *Intellectual Property Rights and Native American Tribes*, 20 AM. INDIAN L. REV. 111, 117-18 (1995-96).

61. *See generally* Varadarajan, *supra* note 51.

62. *Id.* at 385.

63. *See* Pub. L. No. 101-644, 104 Stat. 4662 (1990) (codified as amended in scattered sections of 18 & 25 U.S.C.).

64. *Navajo Nation v. Urban Outfitters, Inc.*, Civ. No. 12-195 BB/LAM, at 1 (D.N.M. filed May 13, 2016).

65. *Navajo Nation v. Urban Outfitters, Inc.*, 935 F. Supp. 2d 1147, 1158, 1169-70 (D.N.M. 2013).

## 2. *Protection of Expression*

Copyright law protects literary and artistic expressions, and is thus the most applicable area of IP protection for the type of TK at issue in linguistic and cultural research.<sup>66</sup> Indigenous groups may wish to secure copyright protection for many reasons, including to ensure that a group's knowledge and folklore are represented in a culturally-appropriate manner, to ensure proper attribution of stories, and to protect the secrecy of sacred or private tales.<sup>67</sup>

Several problems exist for copyright protection of TK. To secure copyright protection, an author must demonstrate original authorship.<sup>68</sup> Folklore, however, is developed and transmitted orally over generations, and a single author may not be identifiable.<sup>69</sup> Collective ownership is not legally cognizable in the copyright regime in the United States, although this is the primary form of ownership that many indigenous groups recognize.<sup>70</sup> Additionally, it is inappropriate in many indigenous groups for an individual to claim ownership of collectively-held stories.<sup>71</sup> While these works might logically be considered jointly authored, under copyright laws the authors must have conceived the work at the same time and agreed to jointly author the work to be considered joint authors.<sup>72</sup>

Additionally, the work must be documented in a fixed form such as written or recorded format—oral transmission alone is not sufficient to satisfy this requirement.<sup>73</sup> The fixation requirement excludes oral performances of TCEs such as folklore and traditional songs from copyright protection, but recordings of the same performances would qualify for copyright protection.<sup>74</sup> Copyright protection, however, only lasts for a limited amount of time, so even if works gain copyright protection, they will enter the public domain at some point.<sup>75</sup> Another limitation on

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66. Newman, *supra* note 52, at 432.

67. *See* Schüssel, *supra* note 54, at 314 (describing reasons Alaska Natives seek measures to protect cultural property); *see also* Newman, *supra* note 52, at 437 (discussing reasons authors wish to protect moral rights).

68. Newman, *supra* note 52, at 440.

69. *See* Schüssel, *supra* note 54, at 324.

70. Riley, *supra* note 50, at 177; Guest, *supra* note 60, at 126.

71. *See* Schüssel, *supra* note 54, at 323-24.

72. *Id.* at 324-25.

73. *Id.* at 318.

74. *Id.*

75. *Id.* at 317, 324 (noting that copyright generally expires seventy years from the life of the author).

copyright protection particularly relevant to TK is the fair use doctrine, which allows use of a copyrighted work for specific purposes including research, scholarship and teaching.<sup>76</sup>

The materials collected in language documentation differ from materials with content that falls exclusively within the scope of TCE in two significant ways. First, although knowledge of the language is fairly considered TK, natural languages themselves are not copyrightable.<sup>77</sup> Language documentation materials may not fall exclusively within the domain of TCE since they often include forms of expression that may not represent the tradition of the community but rather the distinct voice of a single speaker or writer, as in the previous example of the personal history narrative.<sup>78</sup> Second, due to the research methodology used in language documentation research, works are invariably fixed in some form at the time of data collection: in written form, as audio recordings, as video recordings, as photographs, as drawings, or in some combination thereof.

Language documentation methodology solves some of the issues raised by TK for copyright protection; namely, the requirement for fixation. The research consists of recording primary materials on language or cultural practices and then annotating those materials to create secondary materials. Research may take the form of recording someone telling a story, then working with a language speaker to transcribe and translate the story and gain details about its import and context. The joint annotative work between the researcher and the speaker or translator can itself be recorded to create new audio or video records as well as written descriptions and annotations.<sup>79</sup> Since these events are in a fixed medium (recorded or written), they fall within the subject matter that can be protected under copyright in a way that the content of a culture's traditional story itself cannot be.

While documentary research methods offer some solutions for authorship issues, they raise additional issues for copyright in the area of authorship rights. For example, one researcher describes incorporating a video as part of her documentation work in order to document cultural practices as well as language.<sup>80</sup> The researcher worked collaboratively with

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76. Guest, *supra* note 60, at 124.

77. See Newman, *supra* note 52, at 432.

78. See *supra* Section I.C.

79. See, e.g., Salfner, *supra* note 28, at 237.

80. Racquel-María Yamada, *Collaborative Linguistic Fieldwork: Practical Application of the Empowerment Model*, 1 LANGUAGE DOCUMENTATION & CONSERVATION 257, 263 (2007).

the language community, creating the video by filming cassava-bread production.<sup>81</sup> Several people were involved in editing and production.<sup>82</sup> The video was then used as a tool to elicit data: speakers of the language watched the video and narrated the events.<sup>83</sup> The narrations were recorded and became a part of the language documentation. The narrations were analyzed collaboratively by the researcher and the village chief through traditional methods including transcription and translation.<sup>84</sup> This documentation event resulted in materials with different sources, different speakers, and different media (video, audio narration by several persons, transcriptions, and translations).

With several layers of events, the person with the legal status of ‘author’ of an individual piece may be difficult to ascertain. The cultural construct of copyright protection for the individual performing or authoring raises the same disjunctive concerns (of individual ownership as opposed to collective ownership) as other types of TK protections, and may actually be very divisive for a community.

### *C. Other Mechanisms*

#### *1. Federal Legislation*

In recent years, Congress has undertaken some efforts to address issues related to TK and IP. One of the most important developments is the recognition of collective ownership of tangible cultural resources in the framework for the Native American Graves Protection and Repatriation Act (NAGPRA), enacted in 1990.<sup>85</sup> NAGPRA requires federal institutions to repatriate cultural objects regarded by a tribe as the tribe’s collectively-owned cultural property.<sup>86</sup> Another piece of legislation, the IACA, bars non-Native goods from being marked in ways that imply a Native American source.<sup>87</sup> To date, however, there is no legislation that protects Native American expressions of intangible cultural heritage.

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81. *Id.*

82. *Id.*

83. *Id.* at 263-64.

84. *Id.* at 264.

85. Pub. L. No. 101-601, 104 Stat. 3048 (1990) (codified at 25 U.S.C. §§ 3001-3013 (2012)); see Schlüssel, *supra* note 54, at 334.

86. Schlüssel, *supra* note 54, at 334-35.

87. Indian Arts and Crafts Act § 104, Pub. L. No. 101-644, 104 Stat. 4662, 4663 (1990) (codified as amended at 18 U.S.C. § 1159 (2012)).



## 2. Protection Through Tribal Law

An alternative to federal law is for tribes in the United States to enact laws within their own territories to protect intellectual property. Many tribal codes already contain provisions regulating research within tribal territory, and some clarify intellectual property rules for such research.<sup>88</sup> Tribal codes may also contain many different mechanisms for IP protection. One example is the Colorado River Indian Tribes Human and Cultural Research Code (CRIT Code), which requires all researchers to obtain research approval and enter a written agreement with the tribe before beginning research on the reservation.<sup>89</sup> The CRIT Code expressly addresses ownership of intellectual property, claiming collectively “all ownership, property, trademark, copyright, and other rights to cultural, linguistic, and historic information that is not the intellectual property of Researcher.”<sup>90</sup> The tribe requires researchers to submit a manuscript of their results for approval prior to publication and requires researchers to share any monetary benefits from publication.<sup>91</sup> Manuscript approval serves several purposes, including protecting sacred material and securing accurate representations of culture.<sup>92</sup> The CRIT Code requires researchers to acknowledge the Colorado River Indian Tribes as the source of information and requires researchers to provide participants with a statement of rights and access to the intellectual property that researchers acquire from them.<sup>93</sup> The CRIT Code also expressly claims rights associated with copyrights, patents, and trademarks.<sup>94</sup>

As demonstrated by the Colorado River Indian Tribes’ approach, contracts can also protect the IP rights associated with TK. In addition to contracts with tribes, a researcher might be bound by contracts with funding agencies, employers, research participants (through informed consent forms), and community members who work on research projects.

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88. *See generally* Research Ordinance, SILETZ TRIBAL CODE §§ 9.100 to 9.111 (2012); Tribal Research Code, HO-CHUNK NATION CODES tit. 3, § 3 (2005) (designated as “3 HCC § 3”); Navajo Nation Human Research Code, NAVAJO NATION CODE ANN. tit. 13, §§ 3251-3271 (2009).

89. COLORADO RIVER INDIAN TRIBES HUMAN AND CULTURAL RESEARCH CODE § 1-304 (2009), [http://www.crit-nsn.gov/crit\\_contents/ordinances/Human-and-Cultural-Research-Code.pdf](http://www.crit-nsn.gov/crit_contents/ordinances/Human-and-Cultural-Research-Code.pdf).

90. *Id.* § 1-601.

91. *Id.* § 1-404.

92. *Id.* § 1-404.

93. *Id.* § 1-601.

94. *Id.* §§ 1-701 to -703.

Language documentation methodology has shifted toward collaborative models of documentary research, and research structures that involve indigenous community members are gaining increasing attention in the field.<sup>95</sup> One model that is particularly relevant is the subcontractor model. In this model, the academic researcher identifies language community members to function as research assistants to gather data and provide annotations and analysis.<sup>96</sup> The supervising researcher completes contracts with the indigenous research assistants that delineate the nature of the work, terms of payment, and intended uses of the research.<sup>97</sup> In such projects, the researcher often creates the contracts by modifying the consent forms that were designed to inform the research subjects of the nature of the study and the information to be collected.<sup>98</sup> But since consent forms do not consistently describe data ownership rights,<sup>99</sup> the terms of this type of contract may not adequately clarify the usage and ownership rights for the data created through such research.<sup>100</sup>

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95. See Elena I. Mihas, *Subcontracting Native Speakers in Linguistic Fieldwork: A Case Study of the Ashéninka Perené (Arawak) Research Community from the Peruvian Amazon*, 6 LANGUAGE DOCUMENTATION & CONSERVATION 1, 4-6 (2012); see also Akiemi Glenn, *Five Dimensions of Collaboration: Toward a Critical Theory of Coordination and Interoperability in Language Documentation*, 3 LANGUAGE DOCUMENTATION & CONSERVATION 149, 153 (2009) (describing collaborative models of language documentation).

96. See Mihas, *supra* note 95, at 6.

97. See *id.*

98. E.g., *id.* at 9.

99. See *infra* Part III.

100. This brings up a different but important issue of whether a supervising researcher can determine a research assistant's use of analytical materials created as part of the project or recordings that contain the research assistant's own performances, or that are created in a joint authorship model. In *Mihas*, the researcher told the research assistants that they did not have the right to distribute copies of their work for profit due to granting agency restrictions, but it is unclear whether the researcher had the legal right to prohibit the research assistants from profiting from their work. An employer may be able to claim property rights to the product of an employee's innovation if the employee created the product as work for hire. It is not clear, however, what the courts would say about assertions of exclusive rights—in this situation, unless the contract explicitly grants all future rights to the research assistant's work product to the employing researcher, the researcher may only be able to legally assert a "shop right" to use the data, not to control the employee's use of the data. The international nature of many language documentation projects adds further complexity, as it may be a challenging task simply to identify which country's IP laws would apply. See Mihas, *supra* note 95.

### III. Informed Consent

#### A. Legal Framework

The necessity to protect human subjects in research came to the world's attention when the Nuremberg Trials revealed Nazi atrocities in human experimentation during World War II.<sup>101</sup> In 1946, the United Nations adopted the Nuremberg Code, which set out ethical principles in research with human subjects.<sup>102</sup> A primary principle of the Nuremberg Code was that research should only take place if consent to the research was voluntarily given by the research subjects.<sup>103</sup> The Nuremberg Code became the foundation for later standards that were developed internationally in the Helsinki Declaration and domestically in the Belmont Report and U.S. federal guidelines.<sup>104</sup> The Helsinki Declaration was developed in 1964 when the World Medical Association expanded international guidelines in biomedical human research, requiring that each human subject be informed of the goals, methods, risks, and benefits of the study.<sup>105</sup>

Domestically, concerns were raised about unethical research when experiments such as the Tuskegee Syphilis Experiment became publicly known. Over a forty-year period, government researchers who wished to document the disease withheld treatments for syphilis from study participants, who were exclusively from a minority disadvantaged population.<sup>106</sup> Responding to these concerns, Congress charged the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research with the responsibility of identifying the foundational principles for research on human subjects, which resulted in the Belmont Report.<sup>107</sup> The Belmont Report identified three basic ethical principles: (1) respect for persons, (2) beneficence, and (3) justice.<sup>108</sup>

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101. See 1 MARY BERNADETTE OTT & GARY YINGLING, *GUIDE TO GOOD CLINICAL PRACTICE* ¶ 840 (2015) (Ethical Considerations), 2006 WL 3246947; IRVING SEIDMAN, *INTERVIEWING AS QUALITATIVE RESEARCH: A GUIDE FOR RESEARCHERS IN EDUCATION AND THE SOCIAL SCIENCES* 60 (4th ed. 2013).

102. SEIDMAN, *supra* note 101, at 60.

103. *Id.*

104. OTT & YINGLING, *supra* note 101, ¶ 840.

105. Piquemal, *supra* note 16, at 69.

106. ROBERT P. CHARROW, *LAW IN THE LABORATORY: A GUIDE TO THE ETHICS OF FEDERALLY FUNDED SCIENCE RESEARCH* 113 (2010); SEIDMAN, *supra* note 101, at 60.

107. OTT & YINGLING, *supra* note 101, ¶ 840.

108. *Id.*; see also Linda Shopes, *Oral History, Human Subjects, and Institutional Review Boards*, ORAL HISTORY ASS'N, <http://www.oralhistory.org/about/do-oral-history/oral-history-and-irb-review/> (last visited Aug. 20, 2016).

These three tenets serve important functions to protect human research subjects. *Respect for persons* centers around the concept of autonomy and forms the basis for the researcher's obligation to ensure free and informed consent of research participants.<sup>109</sup> *Beneficence* includes the obligation to minimize harms and maximize benefits, and forms the basis of a benefit-risk analysis used to evaluate research in an independent review.<sup>110</sup> The principle of *justice* embodies the obligation of the researcher to ensure that research subjects be equitably selected and treated.<sup>111</sup>

The Belmont Report is the source of federal regulations that relate to research known as the "Common Rule".<sup>112</sup> The concerns and the impact of the Belmont report are also reflected in the widespread presence of the three core principles in ethics statements of professional organizations.<sup>113</sup>

### 1. Federal Regulations

The Common Rule was first published as a model policy in 1991 by the White House Office of Science and Technology Policy and was later adopted by relevant federal agencies as regulations.<sup>114</sup> The Common Rule prescribes procedures for research involving humans for all federal agencies participating in research, for any research conducted in federal prisons, and for any research that receives federal support.<sup>115</sup> The Common Rule describes ethical reviews by an oversight committee and statutory requirements for informed consent.

To receive any federal funding, a research project must pass an ethical review conducted by an Institutional Review Board (IRB). The IRB is responsible for delineating protocols that must be followed to ensure compliance with research protocols in accordance with the Common Rule which include the requirement that research subjects give free and informed

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109. OTT & YINGLING, *supra* note 101, ¶ 841.

110. *Id.* ¶ 842; *see also* CHARROW, *supra* note 106, at 114.

111. OTT & YINGLING, *supra* note 101, ¶ 843.

112. *Frequently Asked Questions and Vignettes*, NAT'L SCI. FOUND., <https://www.nsf.gov/bfa/dias/policy/hsfaqs.jsp#relation> (last visited Aug. 20, 2016).

113. *See, e.g., AFS Statement on Ethics: Principles of Professional Responsibility*, AM. FOLKLORE SOC'Y, <http://www.afsnet.org/?page=Ethics> (last visited Nov. 30, 2016) (reprinted from the February 1988 issue of *AFSNews*); *Principles and Best Practices*, ORAL HISTORY ASS'N (Oct. 2009), <http://www.oralhistory.org/about/principles-and-practices>; *Principles of Professional Responsibility: 1. Do No Harm*, AM. ANTHROPOLOGICAL ASS'N ETHICS BLOG (Nov. 1, 2012), <http://ethics.americananthro.org/ethics-statement-1-do-no-harm/>.

114. CHARROW, *supra* note 106, at 114.

115. 28 C.F.R. § 512.16 (2015); 45 C.F.R. § 46.101(a)(1) (2015).

consent.<sup>116</sup> The creation of third-party IRB oversight (rather than direct governmental oversight) as a regulatory mechanism reflects a conscious policy decision to “decentralize the process of protecting human subjects.”<sup>117</sup>

Universities and research institutions that receive any federal support must create IRB committees that oversee research that takes place at the institution or is conducted by anyone affiliated with the institution.<sup>118</sup> The role of the IRB is to provide an independent review of research in order to ensure that the ethical codes that protect human subjects are followed and to weigh the risks and benefits of the study to ensure that the social benefits of the research outweigh the risk of harm to the individual.<sup>119</sup> An IRB has authority to require additional elements of consent or to approve a procedure which omits or alters the requirements, provided certain conditions are met.<sup>120</sup>

Statutory requirements include provisions for fully informed consent of research participants.<sup>121</sup> The statutory components of informed consent minimally include:

- (1) A statement that the study involves research, an explanation of the purposes of the research and the expected duration of the subject's participation, a description of the procedures to be followed, and identification of any procedures which are experimental;
- (2) A description of any reasonably foreseeable risks or discomforts to the subject;
- (3) A description of any benefits to the subject or to others which may reasonably be expected from the research;
- (4) a disclosure of appropriate alternative procedures or courses of treatment, if any, that might be advantageous to the subject;

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116. 45 C.F.R. § 46.103(b) (2015); 45 C.F.R. §§ 46.107-.117 (2015); *see also* 21 C.F.R. § 56 (2015).

117. SEIDMAN, *supra* note 101, at 61-62.

118. 45 C.F.R. § 46.107 (2015).

119. OTT & YINGLING, *supra* note 101, ¶ 840.

120. 45 C.F.R. § 46.116(c)-(d) (2015).

121. 45 C.F.R §§ 46.111, 46.116-.117 (2015).

(5) A statement describing the extent, if any, to which confidentiality of records identifying the subject will be maintained;

(6) For research involving more than minimal risk, an explanation as to whether any compensation and an explanation as to whether any medical treatments are available if injury occurs and, if so, what they consist of, or where further information may be obtained;

(7) An explanation of whom to contact for answers to pertinent questions about the research and research subjects' rights, and whom to contact in the event of a research-related injury to the subject; and

(8) 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 the subject may discontinue participation at any time without penalty or loss of benefits to which the subject is otherwise entitled.<sup>122</sup>

Researchers conducting research overseas must conform to their institution's IRB requirements as well as the ethical oversight mechanism of the host country.<sup>123</sup> While the Common Rule applies by law only to federally-funded research, most universities and research institutions voluntarily apply the regulations to all research conducted under the auspices of the institution.<sup>124</sup> Other countries have similar provisions to protect human subjects; for example, any research involving human subjects that receives governmental funding in Canada must be approved by the institution's Research Ethics Board.<sup>125</sup> Canada's requirements for informed consent are similar to those in the U.S. Code in many respects but Canada's provisions are more protective of human subjects: additional Canadian guidelines not found in the U.S. Code specify that the information given to the participant be made in "plain language," that participants be informed of the possibility of commercialization of research findings and any potential conflicts of interest. Additionally, Canadian guidelines require

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122. 45 C.F.R. § 46.116 (2015).

123. SEIDMAN, *supra* note 101, at 63.

124. Shopes, *supra* note 108.

125. *See* CANADIAN RESEARCH GUIDELINES, *supra* note 4, at 5.

that participants be provided the information of a person outside of the research team who they can contact with ethical concerns.<sup>126</sup>

The efficacy of IRB review in the social sciences is contested. Some researchers laud the review structure as improving the research process by enhancing the researcher's awareness of ethical considerations.<sup>127</sup> Others believe that IRB reviews impede effective research, and a few even feel that the review process may undermine the ethical conduct of research by imposing inappropriate procedures on the consent process.<sup>128</sup> Issues experienced by researchers often stem from the implementation of IRB review in a process that treats medical and nonmedical research in the same framework.<sup>129</sup> Other issues that particularly implicate (and possibly impede) research on TK include IRB blanket imposition of privacy requirements, overly complex consent forms, consent procedures that are not culturally appropriate, and requirements to destroy primary materials upon completion of research.<sup>130</sup>

## 2. State Law

Under state law schemes, informed consent is limited to the medical context, arising from the tort of battery when a medical patient does not give informed and voluntary consent to research or treatment that is conducted on her.<sup>131</sup> Different protections exist for medical research and medical treatment; arguably, a greater protection is warranted for the research patient because there is greater risk and less individual benefit in research treatments than in medical treatments.<sup>132</sup> Tort law enshrines a duty of medical practitioners to obtain the informed consent of a patient to participate in research before any research is conducted on that patient.<sup>133</sup>

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126. *Id.* at 31.

127. SEIDMAN, *supra* note 101, at 62 (“[A]n IRB review, when done well, almost always leads researchers to a heightened awareness of important ethical issues embedded in their proposed research.”); Claire Bower, *Fieldwork and the IRB: A Snapshot*, 86 LANGUAGE 897, 901 (2010) [hereinafter Bower, *Fieldwork and IRB*].

128. *See, e.g.*, Bower, *Fieldwork and IRB*, *supra* note 127, at 902 (discussing the inappropriateness of imposing written consent forms on participants who cannot read them).

129. *See, e.g., id.* at 900; Denise DiPersio, *Linguistic Fieldwork and IRB Human Subjects Protocols*, 8 LANGUAGE & LINGUISTICS COMPASS 505-06 (2014).

130. *See generally* Bower, *Fieldwork and IRB*, *supra* note 127.

131. Douglas Andrew Grimm, *Informed Consent for All! No Exceptions*, 37 N.M. L. REV. 39, 39-41 (2007); *see also* CHARROW, *supra* note 106, at 110-13.

132. Grimm, *supra* note 131, at 40-41.

133. *See, e.g.*, Roger L. Jansson, *Researcher Liability for Negligence in Human Subject Research: Informed Consent and Researcher Malpractice Actions*, 78 WASH. L. REV. 229,

While tort law has not been extended to create a cause of action outside of the medical research context, it is a widely accepted ethical norm that non-medical research should also follow protocols for informed consent, and to some, the necessity of procedures for informed consent in research surpasses those required for medical treatment.<sup>134</sup>

Although the tort of battery does not apply outside of the medical context, any consent agreement imposes contractual obligations upon a researcher and subjects the researcher to the laws of contract. A researcher may also be bound by an employment contract to adhere to certain institutional requirements (such as an institutionally-created ethical code) when conducting research.

### 3. Tribal Codes

Many tribes explicitly address research that occurs within tribal territory in their codes. For example, the Navajo Nation of the southwestern United States requires any researcher conducting research within tribal territory to have the research proposal reviewed by the Navajo Nation Human Research Review Board and to be issued a permit before conducting research.<sup>135</sup> The Navajo Nation Code requires that informed consent be secured in writing after the participant is informed of risks and the purpose of the research and bars researchers from securing disclaimers of liability during the informed consent process.<sup>136</sup> Violations of the Navajo Nation Code can be remedied by injunctions, civil damages, punitive damages, or other relief in the Navajo Nation court system.<sup>137</sup> The Navajo Nation Code also explicitly claims collective ownership over cultural intellectual property: “Research information and data generated by and about Navajo individuals, communities, culture represent inalienable intellectual properties of the Navajo people and over which the Navajo Nation will provide oversight.”<sup>138</sup> By claiming ownership of cultural intellectual property and the right to oversight, the Navajo Nation effectively adds a layer of collective tribal consent onto the individual informed consent process.

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229 (2003) (“Researchers owe human subjects a duty of care analogous to the special relationship between physicians and patients.”).

134. See Grimm, *supra* note 131, at 41-42 (“The research subject requires a more thorough explanation of the details of the study than if she were simply receiving treatment, especially the study’s potential harmful consequences.”)

135. 13 NAVAJO NATION CODE ANN. §§ 3256, 3262 (2009).

136. *Id.* § 3266.

137. *Id.* § 3271.

138. *Id.* § 3253.



### *B. Ethical Framework*

Professions that engage in research implicating TK have also created self-imposed ethical guidelines for the treatment of research participants, often promulgated by the primary professional associations in their respective fields. These guidelines are presented in the form of best practices, which vary depending on academic discipline. Researchers in oral history, anthropology, linguistics, and folklore hold themselves to standards for ethical research conduct. One issue with existing ethical guidelines is that they vary between professions, so an oral historian and an anthropologist, for example, might collect the exact same data but are likely to follow different practices in gaining consent and in clarifying IP rights. The following section contains an overview of the ethical best practices of these four fields.

#### *1. Oral History*

Of the four disciplines that regularly record TK, the field of oral history is the most protective of the rights of persons being researched in its principles and best practices, as described by the Oral History Association (OHA).<sup>139</sup> The obligations of a researcher include the researcher's responsibility to make clear to the participants that consent to be interviewed is voluntary and that participants can withdraw from an interview at any time or refuse to answer specific questions.<sup>140</sup> Consent can be documented either by signing a form or recording an oral statement of consent.<sup>141</sup> Importantly, the OHA expressly clarifies the ownership rights of interviews that are recorded.

Interviewees hold the copyright to their interviews until and unless they transfer those rights to an individual or institution. This is done by the interviewee signing a release form or, in exceptional circumstances, recording an oral statement to the same effect. Interviewers must ensure that narrators understand the extent of their rights to the interview and the request that those rights be yielded to a repository or other party, as well as their right to put restrictions on the use of the material. All use

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139. *See generally Principles and Best Practices*, *supra* note 113.

140. *Id.*

141. *Id.*

and dissemination of the interview content must follow any restrictions the narrator places upon it.<sup>142</sup>

The OHA directs that plans for preservation and access of recordings should be declared to the participants during the informed consent process and on release forms.<sup>143</sup>

### 2. Folklore

The American Folklore Society (AFS) unequivocally places the interests of their research participants above all other interests in research, as expressly stated in their statement of ethics:

In research, folklorists' primary responsibility is to those they study. When there is a conflict of interest, these individuals must come first. Folklorists must do everything in their power to protect the physical, social, and psychological welfare of their informants and to honor the dignity and privacy of those studied.<sup>144</sup>

Folklore researchers are expected to communicate the goals of the research to participants, protect the privacy of participants unless there is "a clear understanding to the contrary," anticipate potential harms of the research and communicate these possible harms to persons who may be affected.<sup>145</sup>

### 3. Anthropology

The American Anthropological Association (AAA) identifies a primary ethical obligation to do no harm (either direct or inadvertent) that often takes primacy over other responsibilities.<sup>146</sup> The AAA notes that a researcher's lack of transparency about research goals or methodology impacts whether consent is fully informed.<sup>147</sup> The AAA is not protective of the IP rights of participants, noting only that negotiation with participants about data ownership and dissemination *may be necessary* before

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142. *Id.*

143. *Id.*

144. *AFS Statement on Ethics: Principles of Professional Responsibility*, *supra* note 113.

145. *Id.*

146. *Principles of Professional Responsibility: 1. Do No Harm*, *supra* note 113.

147. *Principles of Professional Responsibility: 2. Be Open and Honest Regarding Your Work*, AM. ANTHROPOLOGICAL ASS'N ETHICS BLOG (Nov. 1, 2012), <http://ethics.americananthro.org/ethics-statement-2-be-open-and-honest-regarding-your-work/>.

conducting research.<sup>148</sup> The AAA expects researchers to ensure that participants' consent is fully informed, voluntary, and ongoing, but notes that the form of the consent is not fixed.<sup>149</sup> The ethics statement does not address participant withdrawal. Anthropologists have a responsibility to establish expectations for protection of privacy prior to and throughout the research.<sup>150</sup>

#### 4. Linguistics

In comparison with the other disciplines, the Linguistic Society of America (LSA) ethics statement identifies few meaningful protections of research participants. Researchers have responsibilities to obtain informed consent, ensure that participation is voluntary and consent is ongoing, and maintain expected privacy in regards to the resulting data.<sup>151</sup> The LSA statement contains an obligation to make the results of linguistic research available to the general public, but does not address dissemination to research participants or consideration of benefits to research participants.<sup>152</sup> The LSA identifies the right of research participants to control the recording and access of their contributions with "full knowledge of the potential consequences."<sup>153</sup> In its correspondence, the LSA has identified particular concerns with confidentiality expectations of research oversight bodies, noting that research on language often involves situations where participants expect public acknowledgement of their contributions to the research.<sup>154</sup>

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148. *Id.*

149. *Principles of Professional Responsibility: 3. Obtain Informed Consent and Necessary Permissions*, AM. ANTHROPOLOGICAL ASS'N ETHICS BLOG (Nov. 1, 2012), <http://ethics.americananthro.org/ethics-statement-3-obtain-informed-consent-and-necessary-permissions/>.

150. *Id.*; see also Sue-Ellen Jacobs, *Case 5: Anonymity Declined*, HANDBOOK ON ETHICAL ISSUES IN ANTHROPOLOGY, <http://www.americananthro.org/LearnAndTeach/Content.aspx?ItemNumber=12922&RDtoken=52170&userID=> (describing an ethical case study regarding anonymity).

151. *Linguistic Society of America Ethics Statement* at #2, LINGUISTIC SOC'Y OF AM. (May 2009), [http://www.linguisticsociety.org/files/Ethics\\_Statement.pdf](http://www.linguisticsociety.org/files/Ethics_Statement.pdf) ("Responsibility to individual research participants.").

152. *Id.* at #6 ("Responsibility to the public.").

153. *Id.* at #2.

154. Letter from Sandra Chung, President, Linguistic Soc'y of Am., to Jerry Menikoff, U.S. Dep't of Health & Human Servs. (Oct. 14, 2011), <http://www.linguisticsociety.org/sites/default/files/anprm-comments%20%282%29.pdf>.

### 3. Individual and Institutional Codes

Other organizational codes may exceed the ethical guidelines of a discipline. For example, the School of Oriental and African Studies at the University of London requires researchers affiliated with the university to follow ethical guidelines which include, *inter alia*, “clarify[ing] any intellectual property rights at the outset of the project,” “disseminat[ing] research findings at the earliest opportunity,” and “tak[ing] account of personal and national disparities in wealth, power, legal status of the researcher, and political interests.”<sup>155</sup>

Individual researchers have also suggested that ethical guidelines to be added to the standard protocols. Nathalie Piquemal, professor of education and anthropology at the University of Manitoba, finds existing protocols insufficient for research involving Native American communities and suggests four ethical recommendations for truly informed consent: (1) negotiating responsibilities with the community before beginning research, (2) obtaining consent from the individual and seeking collective consent from the person “recognized [in the community] as the keeper of this particular knowledge,” (3) confirming consent during the research to give participants an opportunity to reflect on their contributions, and (4) providing the community with data.<sup>156</sup> Piquemal’s recommendation to confirm consent is in consonance with recent observations by field linguists that consent should be periodically revisited or ongoing,<sup>157</sup> and with the ethics statements within anthropology and linguistics.<sup>158</sup>

#### C. Issues and Special Considerations for Informed Consent in Research on Traditional Knowledge

Several issues arise when considering the legal and ethical frameworks for research. First, in some cases there may be a conflict between IRB practices in administering federal guidelines and professional codes of

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155. Peter K. Austin, *Communities, Ethics and Rights in Language Documentation*, 7 LANGUAGE DOCUMENTATION & DESCRIPTION 34, 37 (2010).

156. Piquemal, *supra* note 16, at 75-76.

157. BOWERN, *supra* note 1, at 180-82; Rice, *supra* note 1, at 417-18; Laura C. Robinson, *Informed Consent Among Analog People in a Digital World*, 30 LANGUAGE & COMMUNICATION 186, 190 (2010).

158. *See supra* Section III.B.2-3.

ethics,<sup>159</sup> particularly since IRB practices remain based in large part on medical research protocols.<sup>160</sup>

Second, there is a glaring gap with the incomplete protection under the law for research subjects since research that does not receive federal funding is not subject to regulation. This means that any privately-funded research is not subject to the requirements of the Common Rule. Although many universities voluntarily comply with the Common Rule in all research conducted under the auspices of their institutions, this practice is not required by law.<sup>161</sup> Ethical guidelines are not legally binding, so the greater protections espoused by some professions is in effect aspirational.

Third, the legal framework for consent does not address IP rights to the data that is collected; while the Oral History Association expressly recognizes that interviewees hold the copyright to their interviews, the ethical codes for the primary associations in anthropology, linguistics, and folklore address IP rights incompletely or not at all. Without a requirement to clarify data ownership for research that collects TK, it is likely that either the participant or the researcher (or both) lack a clear understanding of the scope of consent that is given. A participant may believe that by participating in the research, she is yielding her rights to the recordings that are made, although no express assignment of ownership has been made. Alternately, a researcher may believe that describing the potential future uses of the data is akin to assigning ownership over the recorded data, rather than a license to use the data, while the participant may believe that by consenting she has granted the researcher a license to analyze the data in only the manners indicated. This issue becomes even more complex when the right to withdraw participation is considered.

If a participant wishes to withdraw from the project, it remains unclear what the implications are for the data already collected: for example, whether the researcher is required to remove all data, including group or conversation data from other participants, and whether the researcher must destroy all notes made on the participant's contribution. If the reason for the participant's withdrawal is a desire to keep certain cultural information

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159. See Austin, *supra* note 155, at 38.

160. See, e.g., Bower, *Fieldwork and IRB*, *supra* note 127, at 901 (“[S]ome IRBs continue to require social scientists to use protocol forms designed for medical and clinical methodologies.”).

161. See CHARROW, *supra* note 106, at 116; see also Bower, *Fieldwork and IRB*, *supra* note 127, at 898 (finding in a recent survey of language documentation researchers that although most research—88%—was subject to some form of ethical oversight, some research was not).

from being published in accordance with community wishes for privacy, the researcher's conduct and use of information is implicated in both the legal and ethical realms.

Fourth, the context of research involving TK raises particular issues of informed consent, such as (1) ensuring that participants understand the scope of their consent, including how their contributions will be used and who will have access to the data, (2) reconciling individual informed consent with ideas of collective ownership and the role of the community, and (3) issues with withdrawal where a goal of the research is to create an archival record.<sup>162</sup> These issues are particularly pervasive in the context of language documentation.

One ethical tenet of linguistic research is the responsibility to archive data and make data publicly available.<sup>163</sup> Another ethical principle is to do no harm.<sup>164</sup> Language documentation entails the creation of a complete record of a language and results in a plethora of media and forms of expression as research progresses.<sup>165</sup> Those creations are implicated by copyright law and issues of authorship and data ownership,<sup>166</sup> as well as by tribal laws, professional ethical codes, and considerations in cross-cultural ethics. Ethical appropriateness varies with the cultural context of the research,<sup>167</sup> and ethical conflicts inevitably arise. The following section will address particular aspects of informed consent in collection of TK, considering the issues raised by the ethical standards described above for the Common Rule requirements.

### *1. Description of the Study*

Among other things, researchers should inform participants of the purposes of the research, provide the expected duration of participation, and

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162. See BOWERN, *supra* note 1, at 172; Steven Bird, *Cyberlinguistics: Recording the World's Vanishing Voices*, CONVERSATION (Mar. 10, 2013), <http://theconversation.com/cyberlinguistics-recording-the-worlds-vanishing-voices-12644> (proposing that a participant's understanding of potential uses outside of personal knowledge could be informed by analogy with experiences within the cultural context); Glenn, *supra* note 95; see also Mihas, *supra* note 95 (describing an example of implementation of informed consent procedures); Salfner, *supra* note 28 (same).

163. See Dwyer, *supra* note 1, at 40; see also *Linguistic Society of America Ethics Statement*, *supra* note 151, at #6.

164. Dwyer, *supra* note 1, at 38.

165. See Himmelmann, *supra* note 26, at 1.

166. See generally Newman, *supra* note 52, at 430.

167. Rice, *supra* note 1, at 413.

describe the procedures.<sup>168</sup> In language documentation, however, it is not always a straightforward task to describe the procedures in advance, due to the open-ended nature of the research<sup>169</sup> and the increasing use of emergent research methodologies.<sup>170</sup> Emergent methods involve the research participant in the direction of research by using open-ended questions and shifting focus to new topics as they arise.<sup>171</sup> Some researchers rely on non-verbal stimuli to investigate a particular linguistic or cultural feature, displaying pictures or showing videos and encouraging the participant to make observations with varying degrees of guidance from the researcher.<sup>172</sup> A researcher may use a recording made as part of the research project as an elicitation tool itself.<sup>173</sup> Since the goal of language documentation is to create a complete record of the language as it is naturally spoken, emergent methodology is particularly appropriate for this goal. Emergent methods also allow research participants a role in determining the direction of research, fostering the collaborative approach between researcher and participant.<sup>174</sup>

When language revitalization is a research goal, collaboration between the researcher and research participants allows the researcher to collect data of interest to the language community, resulting in research that is of greater collective benefit. Some researchers structure their research around community input from a framework of collaboration.<sup>175</sup> Undoubtedly, such a relationship is of greater benefit to the research community than the traditional research model in which the researcher determines the parameters of research and participants are mere sources of information. However, this relationship does not fit well within the traditional research

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168. 45 C.F.R. § 46.116(a)(1) (2015).

169. See Robinson, *supra* note 157, at 189.

170. Bower, *Fieldwork and IRB*, *supra* note 127, at 904.

171. See *Id.*

172. See, e.g., Asifa Majid, *A Guide to Stimulus-Based Elicitation for Semantic Categories*, in THE OXFORD HANDBOOK OF LINGUISTIC FIELDWORK, *supra* note 1, at 54, 56 (describing the benefits of stimulus-based elicitation). For a cross-cultural comparison of the use of a video as a research stimulus, see generally THE PEAR STORIES: COGNITIVE, CULTURAL, AND LINGUISTIC ASPECTS OF NARRATIVE PRODUCTION (Wallace L. Chafe ed., 1980). For a cross-linguistic comparison of the narration of a wordless picture book, see generally RUTH ARONSON BERMAN & DAN ISAAC SLOBIN, RELATING EVENTS IN NARRATIVE: A CROSSLINGUISTIC DEVELOPMENTAL STUDY (1994).

173. See Yamada, *supra* note 80, at 263-64.

174. See Rice, *supra* note 1, at 418-20.

175. See Racquel-María Yamada, *Integrating Documentation and Formal Teaching of Kari'nja: Documentary Materials as Pedagogical Materials*, 5 LANGUAGE DOCUMENTATION & CONSERVATION 1, 4-5 (2011).

model articulated by federal guidelines for informed consent.<sup>176</sup> A few researchers report that their IRB required them to submit an exhaustive list of questions in advance.<sup>177</sup> It is ironic that federal guidelines which were created to enhance research participants' rights are in this instance hampering the ability of a researcher to give the participants greater control over their participation.

## 2. Risks

Much linguistic research is considered low-risk by IRBs and therefore eligible for expedited review or exempt from review under federal guidelines.<sup>178</sup> However, there are several risks to the individual and the language community that should be considered from an ethical perspective. Individuals may experience emotional pain if narrating an uncomfortable memory.<sup>179</sup> Payments for participation or research assistance may disrupt the local economy.<sup>180</sup> Research results could bring unwanted governmental attention or be used against the language community in legal proceedings.<sup>181</sup> While researchers may be able to mitigate these risks with proper attention,<sup>182</sup> it is not possible to completely eliminate them.

A particular risk in the collection of TK is the potential for future uses that are culturally inappropriate. First, making traditional stories public may open a door for cultural appropriation by outsiders.<sup>183</sup> Second, recordings can reveal incriminating or embarrassing facts about an individual or family, or even sacred or secret material.<sup>184</sup> Even if particular content is not secret, it may be used in a way that is considered culturally inappropriate;

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176. See Bower, *Fieldwork and IRB*, *supra* note 127, at 897; 45 C.F.R. § 46.116(a)(1) (2015). See generally Racquel-María Yamada, *Speech Community-Based Documentation, Description, and Revitalization: Kari'nja in Kononmerume* (Sept. 4, 2010) (unpublished Ph.D. dissertation, University of Oregon) (on file with ProQuest Dissertations & Theses Global) (describing a research framework for language documentation based on collaboration between researcher and speech community as equal partners).

177. Bower, *Fieldwork and IRB*, *supra* note 127, at 899.

178. See DiPersio, *supra* note 129, at 506.

179. See SEIDMAN, *supra* note 101, at 67.

180. BOWERN, *supra* note 1, at 158.

181. *Id.*

182. See *id.* at 159.

183. See generally Rebecca Tsosie, *Reclaiming Native Stories: An Essay on Cultural Appropriation and Cultural Rights*, 34 ARIZ. ST. L.J. 299 (2002) (describing harms that result from cultural appropriation of Native cultures).

184. Robinson, *supra* note 157, at 188.



for example, in some cultures certain stories may only be told at certain times of the year or only by certain persons.<sup>185</sup>

One example is found in Barre Toelken's description of an ethical conflict involving his research on Navajo stories.<sup>186</sup> Toelken collected stories for more than forty years, working principally with Hugh Yellowman.<sup>187</sup> Certain stories and songs are only performed at certain times of the year, and Toelken was allowed to record these stories for teaching and research because he promised to only play the recordings at appropriate times of the year.<sup>188</sup> Navajo persons considered the sounds dangerous when they were spoken if they were released into the air at improper times (for example, one person considered it permissible to listen with earphones, since sounds were not transmitted aloud).<sup>189</sup> After Yellowman passed away, his widow expressed concern that someone hearing the stories or saying the words during the wrong season could be injured.<sup>190</sup> Legally, Toelken was not bound to take any action, but ethically, Toelken recognized competing obligations. Toelken was conflicted between an "academic sacrilege" in destroying the recordings and the "personal and cultural sacrilege" of keeping the tapes against the wishes of his adopted Navajo family.<sup>191</sup> Ultimately, Toelken returned the tapes to the family.<sup>192</sup> In this act, Toelken did not rely on issues of data ownership,<sup>193</sup> but took measures to avoid a risk of cultural harm that had not been anticipated when the actual recording had taken place.

From this example, two principles can be gleaned that are integral to assess the risks of a study in a manner appropriate for research on TK. First, a researcher must take measures to revisit the use of the data and the context surrounding the data collection to ensure that unanticipated risks have not arisen since the time of data collection. Second, a researcher must take steps to become sufficiently culturally competent to recognize the risks of harm to the community that the research may create. This may involve consultation with a third party, which is one of the reasons to seek third

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185. BOWERN, *supra* note 1, at 179; Tsosie, *supra* note 183, at 303.

186. *See generally* Toelken, *supra* note 39.

187. *Id.* at 381.

188. *Id.*

189. *Id.* at 383.

190. *Id.* at 385.

191. *Id.* at 385-86.

192. *Id.* at 385.

193. *Id.* at 386-87.

party consent from a knowledge keeper or cultural representative of the community.<sup>194</sup>

### 3. *Benefits*

Just as the risks in documentary research involve both the individual and the collective, the possible benefits also extend beyond the individual. The individual may benefit through monetary compensation, and it is increasingly common for some sort of contribution to also be made to the language community, either in pecuniary terms or in a labor exchange.<sup>195</sup> Providing copies of research data may benefit a community working on language revitalization, and will also benefit the scientific community as a whole by contributing to the understanding of human language.<sup>196</sup> An individual participant or a language community may benefit from having contributions recorded and fixed for the purposes of copyright law. More broadly, society benefits from the preservation of vital knowledge that may otherwise be lost.

### 4. *Confidentiality*

The Common Rule does not require confidentiality, but rather that a researcher describe how (and if) the confidentiality of the subject's identity will be preserved.<sup>197</sup> In practice, however, some IRBs may not approve a research project that does not preserve complete privacy of participants,<sup>198</sup> and some cases have been reported where IRBs have required destruction of primary research materials.<sup>199</sup> These reports exemplify issues with the inconsistency of IRB review and the imposition of a model of review based on a medical research paradigm. While these reports may represent a minority of cases,<sup>200</sup> it is clear that appropriate measures for confidentiality in documentary research are best determined on a case-specific basis.<sup>201</sup> Recognition for contributions may actually benefit a research participant (for example giving increased prestige to the participant or to the status of

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194. See, e.g., Piquemal, *supra* note 16, at 76.

195. See Dwyer, *supra* note 1, at 39.

196. See generally Naomi Palosaari Fox & Steven Moran, *Non-traditional Dissemination of Fieldwork: From the Field to the World*, 27 U. OF WASH. WORKING PAPERS IN LINGUISTICS 109 (2008).

197. 45 C.F.R. § 46.116(a)(5) (2015).

198. Bower, *Fieldwork and IRB*, *supra* note 127, at 903.

199. *Id.* at 901-02.

200. *Id.* at 901.

201. See Rice, *supra* note 1, at 418.

the language itself),<sup>202</sup> and some individuals or communities may have a strong desire for acknowledgment.<sup>203</sup> Additionally, if research is conducted in a collaborative way, or if the research participant's material qualifies as a copyrighted creation, omission of recognition may be a violation of the moral rights of the participant to receive recognition for authorship.

##### 5. *Voluntariness*

Although there is general agreement that consent should be voluntary and ongoing,<sup>204</sup> the particular environment of language documentation poses pragmatic issues in ensuring the ongoing structure of consent. One issue is the treatment of data and knowledge gained from the research if a participant wishes to withdraw her participation. This issue is particularly complex when there is a question of whether the TK that the participant contributed is the property of the participant or the community. For example, the goal of language documentation is to create a complete record of the language. Responsible archiving is a primary research responsibility.<sup>205</sup> This may also be consonant with the goals of the language community. Destroying records of the language would be antithetical to these goals, and would create a difficult decision when ownership of the data is contested.<sup>206</sup>

Voluntariness of consent is also implicated by the description of how the data will be used. A participant's consent cannot be considered truly voluntary without a complete understanding of who will access the data and how the data will be used.<sup>207</sup> Researchers are confronted with the difficult task of considering as many potential uses of data as possible and explaining those uses in a culturally contextualized manner.<sup>208</sup> There are inherent difficulties in ensuring that consent is fully informed if the uses to which the data will be put are not present in the environment of the research participant.<sup>209</sup> Explaining the use of data as examples for presentation in

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202. See, e.g., Austin, *supra* note 155, at 47-48 (discussing the results that communities value, which can include appreciation of a community's language efforts and physical objects such as dictionaries that represent the research project).

203. See Rice, *supra* note 1, at 418.

204. See, e.g., BOWERN, *supra* note 1, at 153.

205. Dwyer, *supra* note 1, at 40-41.

206. See *id.* at 41-42 (recommending that the researcher be explicit about the consultant's future rights at the time of the recording).

207. See Dwyer, *supra* note 1, at 43; see also Robinson, *supra* note 157, at 188-89.

208. See Dwyer, *supra* note 1, at 43; Rice, *supra* note 1, at 417-18 (identifying potential ethical issues for the novice fieldworker).

209. See generally Robinson, *supra* note 157.

professional conferences, for example, is an alien concept to a participant who lives in a house without electricity or internet connection and who has had no substantive contact with higher education.<sup>210</sup> Additionally, as technology changes and new potential uses become possible, a researcher may have difficulty revisiting consent if the research environment is remote or the participant has passed away.

#### 6. Form and Method of Consent

Federal regulations require consent to be in written form but allow an IRB to waive this requirement if there is a concern about confidentiality and the document would be the only link to the participant, or if the risk of harm is minimal.<sup>211</sup> Applied strictly, this regulation represents perhaps the greatest mismatch between federal guidelines and the mandates of ethical research. Although some researchers are able to obtain permission from their IRBs to gain oral consent, many IRBs require that consent be in writing.<sup>212</sup> Linguistic research is often considered low-risk and thus could qualify for exemption from the consent process under federal regulations,<sup>213</sup> but IRB boards tend to require that written consent be obtained in any case.<sup>214</sup>

Several researchers have noted problems with a blanket requirement for written consent forms, particularly when research participants are not literate or in cultures where written forms are mistrusted.<sup>215</sup> A written form that includes all of the information required by an IRB may be overly complex and not easily understood by the participant, and reliance on written forms may result in researchers failing to provide thorough oral explanations.<sup>216</sup> Written forms may create a “suspicious tone” and set up an overly authoritative power structure.<sup>217</sup> Requiring a written form in situations where written forms are culturally inappropriate conflicts with a researcher’s ethical obligation to respect cultural sensitivity.<sup>218</sup> It is possible to provide sufficient information to meet the standards laid out in federal

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210. See Robinson, *supra* note 157, at 189. *But see* Bird, *supra* note 162.

211. 45 C.F.R. § 46.117 (2015).

212. Robinson, *supra* note 157, at 188.

213. DiPersio, *supra* note 129, at 506.

214. See Robinson, *supra* note 157, at 188.

215. See, e.g., *id.*; DiPersio, *supra* note 129, at 507.

216. See SEIDMAN, *supra* note 101, at 77.

217. *Id.* at 77-78.

218. Chloe Skinner, ‘You Can Be Jailed Here by Even Me Talking to You’: Dilemmas and Difficulties Relating to Informed Consent, Confidentiality and Anonymity, in FIELDWORK IN THE GLOBAL SOUTH 183, 185-86 (Jenny Lunn ed., 2014).

guidelines with a principled oral consent process; for example, some linguists use oral scripts or checklists to ensure that consent is fully informed.<sup>219</sup>

There are special considerations inherent to the context of research on TK that transcend the individual research participant and involve the role of the language community and ownership of the cultural resource being researched. Tribes are becoming more involved in intellectual property issues that arise from data collected in a research context.<sup>220</sup> There is an increasing emphasis in documentary research on collaboration with the community being researched, which some researchers regard as an ethical imperative that includes providing benefits of the research to the language community.<sup>221</sup> Some native communities regard the native language as a community resource, rather than an individual competency.<sup>222</sup> In this instance, the issue is whether gaining the consent of some third party in the community is an obligation imposed on a researcher.<sup>223</sup>

Since much TK is communally held, an individual may not have the authority to consent to the dissemination and use of TCEs that express the community's heritage and cultural values.<sup>224</sup> There is a risk that the community may be harmed by the sharing of knowledge in ways that an individual may not anticipate. Among others, Professor Peter Austin recommends that the researcher's responsibilities include ascertaining whether third party consent is needed and gaining that consent before publishing data, even if such consent is not legally required.<sup>225</sup>

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219. Robinson, *supra* note 157, at 188. In my own research, I found that references to written forms and materials caused embarrassment for participants who were illiterate or had low levels of literacy; I addressed these issues by adopting the methodology of recorded oral consent.

220. Hinton, *supra* note 24, at 40.

221. *Id.* at 35 (“[A] major change in linguistic ethics has taken place (as it has throughout anthropology as well), such that it has become a given that linguistic research must also serve the interests of the community whose language is being documented.”); CANADIAN RESEARCH GUIDELINES, *supra* note 4, at 107 (“[E]ngagement with community is an integral part of ethical research involving Aboriginal peoples.”).

222. See Hinton, *supra* note 24, at 40 (“In yet other cases, the heritage language is being newly viewed by the tribe as the actual property of the tribe as a legal entity . . .”).

223. See, e.g., Austin, *supra* note 155, at 39 (discussing the ethical obligation of the researcher to gain third party consent).

224. See Rice, *supra* note 1, at 411 (describing the researcher's obligation to ascertain whether a community considers language to be corporate knowledge and which members of the community have authority to consent).

225. Austin, *supra* note 155, at 39; see also Rice, *supra* note 1, at 411; Nikolaus P. Himmelmann, *Documentary and Descriptive Linguistics*, 36 LINGUISTICS 161, 172-76

The question of whether an individual can consent to research on TK is further complicated in situations where there may be internal community disagreement about who has the authority to consent or conflicting views within a community about whether language is the IP of the individual speaker or the collective.<sup>226</sup>

#### *7. Participant Rights*

According to federal regulations, participants should be informed that they can discontinue participation at any time and that they have the right to withdraw data already contributed.<sup>227</sup> This requirement obligates researchers to (1) consider the issues that withdrawal poses to any specific methodology (such as language documentation), (2) plan for how they will manage such requests prior to beginning the research, and (3) explain these measures to participants when appropriate.<sup>228</sup>

Researchers should also inform participants of their rights regarding data to ensure that the consent process has actually been fully informed from the ethical as well as the legal perspective. This includes a fully delineated informed consent process clarifying and assigning the rights to the data to be collected. Researchers should take particular care to observe ethical principles relating to appropriation of TK and consider whether the material constitutes TCE. If the material collected falls within the domain of TCE, this step may constitute a usage license for the researcher, such as the provisions included in the Oral History Association's ethical statement. For example, the researcher and research subject might agree that the researcher may use the data collected for research purposes, and agree that the researcher owns the analysis of the data and may display or publish the data in the ways agreed upon in the informed consent form. If the researcher desires to make any additional usage, she may need to secure the permission of the research subject.

### *IV. Ways Forward*

#### *A. Research Practice*

A revised approach to informed consent is necessary when research involves TK. Existing legal standards are not sufficient: researchers should

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(1998) (discussing the responsibility to respect community wishes for privacy when collecting language data).

226. Hinton, *supra* note 24, at 41.

227. See 45 C.F.R. § 46.116(a)(8) (2009).

228. See *supra* Section III.C for questions to be considered regarding withdrawal.

be held to culturally-appropriate ethical standards. But researchers should not be hampered by the stringent application of bureaucratic IRB practices that do not further ethical research goals. A researcher should ensure that any research involving TK takes into account the Belmont principles of beneficence, justice, and respect for persons.

*Beneficence* requires that the risks are outweighed by the benefits of the research. Researchers in language documentation should “do no harm,” and “do some good.”<sup>229</sup> This requires that researchers ensure protection of secret, private, or harmful information, and consider effects on the community as well as on the individual. This also requires giving recognition to research participants as contributors when they so wish.

*Justice* requires that researchers treat research participants equitably. Since research on a particular language limits the possible selection of research participants to a particular group of individuals, the principle of equitable selection of participants is not necessarily appropriate. However, an analogous application of this principle includes treating participants from different cultures with equal respect, expressed in culturally appropriate attitudes and methods. A researcher from outside the community should ensure that her methodology is as respectful and appropriate in the culture of the community being researched as it would be in her own.

*Respect for Persons* is founded on respect for individual autonomy. An individual should give consent to participate in research only after being fully informed of the nature of the research and the risks and benefits of participation. For research on TK, such consent should include four elements:

(1) Participant’s right to determine confidentiality—whether her identity is kept private or whether she is publicly acknowledged. Along with this, participants should be informed of the researcher’s methods in preserving confidentiality and any risks that confidentiality may be breached.

(2) Participant’s right to fully informed consent, including final consent after data collection has been completed. This includes the right to discontinue the research at any time and the right to withdraw data already recorded. This also includes the right to determine the privacy levels of data, including who may access and use the data and in what forms the data may be disseminated.

(3) Participant’s retention of any IP rights inherent to her contribution. This necessarily involves the right to know what IP rights the participant

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229. Dwyer, *supra* note 1, at 38-39.

may have, what authorship structure exists for different types of data, and what usage license is being granted to the researcher. This also entails providing copies of the collected material to the participant, if desired.

(4) Participant's right to information and consent in a form and method that can be understood. Information and consent may be given in written form or orally as appropriate to the cultural context and individual's needs.

### *B. Implementation*

To ensure compliance with minimal ethical standards in research on TK, individual researchers and professional organizations should revisit their research practices to ensure that they operate with due consideration of the special circumstances inherent to research on TK. Professional organizations would be well-advised to address TK concerns within their ethical guidelines, incorporating principles such as those proposed in Part IV.A. Tribes that have not already done so may wish to incorporate provisions for research oversight and third party consent within their tribal codes.

An option for legal protection is the enactment of legislation to address concerns relating to a tribe's intangible cultural heritage. Congressional action to address Native American concerns about cultural heritage is appropriate due to the federal trust obligation to tribes and is authorized by Congress's exercise of plenary power, as exemplified in similar protective legislation in recent years for repatriation of cultural artefacts (NAGPRA) and protection of Native American trademark rights (IACA).<sup>230</sup> Congress can pass legislation that protects tribal intangible cultural property that could include provisions on research aimed at federally-recognized tribes or taking place on tribal land.

Such legislation might expressly recognize principles on which there is growing international consensus, including access and benefits sharing,<sup>231</sup> which are already addressed by some tribes in their tribal codes. One component of intangible cultural heritage protection should be the requirement that any person wishing to do research involving TK must secure informed consent of individual participants and the approval of any research by the recognized tribal authority. One powerful protection would be the express recognition of tribal governmental jurisdiction over research that takes place on intangible cultural heritage. Congress has given

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230. NAGPRA, Pub. L. No. 101-601, 104 Stat. 3048 (1990) (codified at 25 U.S.C. §§ 3001-3013 (2012)); see IACA, Pub. L. No. 101-644, 104 Stat. 4662 (1990) (codified as amended in scattered sections of 18 & 25 U.S.C.).

231. See *supra* Section II.A.



increasing emphasis to tribal self-determination in recent years by passing several acts to strengthen tribal autonomy such as the Indian Self-Determination and Educational Assistance Act<sup>232</sup> and the Indian Tribal Energy Self Determination Act.<sup>233</sup> Congress recently expanded tribal authority to prosecute non-natives who commit violence against Native American women on tribal land in the 2013 renewal of the Violence Against Women Act.<sup>234</sup> At present, tribes have no criminal authority and limited civil authority over non-Indians,<sup>235</sup> requiring reliance on exclusion from tribal land or remedies through contract law. Express recognition of tribal authority would allow tribes to create and enforce culturally-appropriate rules and avoid complex jurisdictional analyses.

#### V. Conclusion

Current research practices based on the existing framework of legal and ethical requirements for informed consent do not adequately address research on intangible cultural heritage. Researchers who collect traditional knowledge should follow a principled approach to data collection that aligns with culturally-appropriate ethical norms as well as legal expectations. Informed consent procedures, by their design, disclose to the participants what the researcher intends to do with the data, what rights the researcher has to use the data, and what measures the researcher will take to protect the data and the subject's confidentiality.

In contrast, while some individual researchers and organizations have declared that clarification of intellectual property rights is a research "best practice," there is no requirement that a researcher inform the research participants of any rights to the data she is contributing. While many researchers in collaborative model projects do provide the participants with copies of the research materials, this step is not required. Under the traditional research model, the informed consent process was conceived to protect the research subject, but researchers should also understand that the

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232. Pub. L. No. 93-638, 88 Stat. 2203 (1975) (codified at 25 U.S.C. §§ 450-458 (2012)).

233. 25 U.S.C. §§ 3501-3506 (2012).

234. *Violence Against Women Act (VAWA) Reauthorization 2013*, U.S. DEP'T OF JUSTICE (last updated Mar. 26, 2015), <http://www.justice.gov/tribal/violence-against-women-act-va-wa-reauthorization-2013-0>.

235. For criminal jurisdiction, see *Oliphant v. Suquamish Indian Tribe*, 435 U.S. 191, 212 (1978) ("Indian tribes do not have inherent jurisdiction to try and to punish non-Indians."). Tribal civil jurisdiction over non-Indians involves a nuanced analysis, established by the Supreme Court in *Montana v. United States*, 450 U.S. 544 (1981).

informed consent process, with no subsequent license or agreement, constrains the researcher's use to exactly the terms described in the process.

It is therefore in the best interests of both the researcher and the participant, as well as a requisite component of truly informed consent, to understand clearly what the participant is consenting to, on what terms the researcher can use the data that is collected, and who retains ownership and control of the content that is created. Researchers also need to consider the risks and benefits of the research to the community, and ensure that consent is ongoing and provided by appropriate third party authorities or community knowledge keepers as well as by the individual participants.