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In Pursuit of Indigenous Intellectual Justice: The Cultural and Health Institutional Review Boards of the Eastern Band of Cherokee Indians

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Cover Page Footnote

TJ Holland, a member of the EBCI, passed away after he wrote this article on September 12, 2020.

Introduction

As sovereign nations, Tribes have the right to decide how to engage with research conducted in their community and Tribes can approve or disapprove of research conducted on their lands by establishing their own research requirements. Prior to the 1970s, research with American Indian and Alaska Native (AI/AN) communities was pursued with little or no oversight from the Tribe. Between the 1970s and 1990s, Tribal councils began to review and approve research in their community and more recently, many AI/AN communities developed their own process for research oversight and accountability (Around Him et al., 2019; Henderson, 2018). Tribes are taking on a greater role in research in their communities due to a concern that relying exclusively on university-based institutional review boards (IRBs) is inadequate with respect to research protections for their members. As of April 2019, there were 50 entities providing research oversight for AI/AN communities (Around Him et al., 2019).

Eastern Band of Cherokee Indians' History with Research

Prior to 1998, anyone who wanted to conduct research on the Eastern Band of Cherokee Indians (EBCI) Tribal lands had to present and discuss their project before Tribal Council. If approved, the Council would produce a Tribal Resolution providing the researcher(s) with permission to conduct their activities in the community. This, of course presented a bilateral problem; with no review period for anyone to review a research project, both Tribal Council and the researcher may only have a few minutes to present their project. After a short question and answer period, one vote would dictate the fate of the entire project. Without a review period in which partnerships and relationships could be established, research tools reviewed, and time to clarify research goals, research and researchers earned a negative reputation within the community and more than a few articles were published that were wanting for accuracy.

In 1993, one such research study was approved. It was a longitudinal study of more than 1,400 children and adolescents that included 11 western North Carolina counties, with an over-sample of children in the EBCI communities. Participants were interviewed multiple times from ages 9 to 21 years with a short break between 16 and 19 years old. More than 11,000 interviews were recorded with over 7,000 blood spots collected. Multiple researchers and faculty from a variety of institutions were involved and published more than 100 articles on their findings and received at least 16 independent National Institutes of Health's awards to support this research since 1998 through 2021. The study enhanced the careers of faculty and future faculty as it came into national awareness after newspapers. For instance, the Washington Post (Oct. 8, 2015) caught wind of the "remarkable thing" of a poor community coming into a significant increase of money when the EBCI started casino gaming about five years into the study (Ferdman, 2015). Researchers were thrilled as this major intervening factor changed the course of their results. A collaborating researcher who co-authored several related articles said "It would be almost impossible to replicate this kind of longitudinal study, especially for a sample this large. This is the sort of circumstance you dream of as a researcher." Yet, many who lived and worked in the EBCI community felt that the study was inappropriate as it did not directly benefit the EBCI community.

Creation of Tribal Research Review Process

In 1998, two IRBs were established, a Cultural IRB and a Medical IRB, by Tribal resolution. The IRBs were created due to the large number and diversity of research requests to the EBCI and the receipt of a federally-funded grant that included research with human subjects. Also, there was broad community consensus that EBCI needed a formal process to review requests to ensure the Tribe's interests were protected, the research was culturally appropriate, and the Tribe

would have data control. This new process still included Tribal Council making the final decision as to whether a research study was approved or rejected.

There are a variety of considerations that one must process before formally applying to conduct research in the community. The EBCI Cultural IRB does not accept any research projects dealing with traditional medicine or religious practices. The EBCI Cultural IRB has seen more than a few requests to “study Cherokee religious practices” to “learn about Cherokee gods and goddesses” or to “learn about Cherokee traditional medicine.” Such information is deemed inappropriate for dissemination outside of the Tribe. Acquisition of traditional knowledge is not considered a right, but a privilege and an attitude of entitlement does not serve the researcher well. The adage that “your question does not instill in me a sense of obligation” applies to this subject. The concept of freedom of inquiry does not apply to traditional EBCI ceremonial knowledge. Certain traditional knowledge is given on a need-to-know basis, and the need to know is generally in context of a particular situation. When taken out of context, the knowledge is, at best, of no use and worse, misapplication of such knowledge may render it useless and cause harm. Much like the paradigm of Indigenous research outlined by Professor Linda Tuhiwai Smith (1999), those who want to conduct research in an Indigenous community should shift their thinking from the “Western” approach of knowledge accumulation to questions like: Is my project going to benefit the Tribal community? Am I providing a desired service?

Tribal Values Related to Research Pursuits

In this light, the Cherokee concept of *du yu k ta i* is about balance. *Duyuktai* is literally translated as “the right way.” This term can be applied to various everyday tasks and more philosophically as a way of life. This concept also implies that there are incorrect ways to act. This can extend to include the motivations of an individual, and in this case, a researcher. Studies

require the taking of informant's time, knowledge, and experience and reciprocity of benefit is expected. It is imperative that the researcher's project is of benefit not only to the informant, but to the Tribe. This reciprocity is perceived as the right way to conduct research among Tribal members.

It is also prudent to remember that few Tribal members are impressed by titles or degrees. Tribal members will judge a researcher on their character and their motives for conducting research, rather than their degrees and what institution they represent. The success of any research conducted with Tribal members is dependent on the *relationships* built with people in the community. These relationships must be built on trust between the researcher and community member. The Tribe as whole must be confident that a research project will help the community in some measurable way.

It is important to understand that there may be some Tribal members who want no part of having an outsider come to conduct research. Native people have had a long history of researchers coming into communities to exploit them for their knowledge, culture, and/or resources and never return. Some of the earliest research experienced by Cherokee peoples was ethnographic work conducted by John Lawson who was a surveyor who wrote about Cherokees' lifeways in his book *A New Voyage to Carolina* in 1709 (Lawson, 2001). Even Lieutenant Henry Timberlake, a military emissary for the British, wrote extensively in his 1760s memoirs about the Cherokee people and their culture which has been cited by historians and anthropologists for centuries (Timberlake, 2007). Therefore, there is a sense of research fatigue among many community members.

EBCI's two IRBs have articulated their values and needs with respect to research, which are listed in Table 1. These are values of the members and what we look for in researchers seeking community entree. The Tribe prefers research projects that address community-identified priorities

and do not impose on the time and effort of Tribal employees. If projects are dependent on Tribal employees, conversations about such needs should be had in advance. EBCI IRB is supportive of researchers who have already engaged with relevant persons at the Tribe in the conceptualization and development stages of a study. Unlike what most academic researchers are accustomed to, data generated from approved research on EBCI Tribal lands belong to the Tribe. Lastly, projects that can generate subsequent funding potential for EBCI services and programs are encouraged.

Table 1. Values and Needs of the Eastern Band of Cherokee Indians' Institutional Review Boards	
Values	
	Trust
	Respect
	Self-determination
	Mutuality of interests
	Full participation
	Reciprocity
	Collective benefit
	Long-term commitment
Needs	
	Projects that are relevant by addressing community priorities
	Projects that are culturally sensitive with processes that are culturally congruent
	Requests that do not demand additional time from staff
	Project partners that are willing to work with and in the community
	Information and data control ultimately in the hands of the Tribe
	Projects that create funding potential or service expansion

EBCI IRBs also consider the following set of questions posed by Smith (1999) when reviewing a research protocol application: Whose project is it? Whose interests does it serve? Who will benefit from it? Who has designed the project? EBCI IRB members also consider the following questions about the investigator and/or investigative team when reviewing their research

protocol application: Is their spirit clear? Do they have a good heart? What other baggage are they carrying? Are they useful to us? Can they fix our generator? Can they actually *do* anything?

Practical Considerations for Potential Researchers

The EBCI process for project review and approval is long and can create havoc with timelines. Even after the research protocol application has been submitted to the proper IRB, the Board may have to meet more than once, may request more information, and/or have questions/revisions about the data collection approach or other methodological aspects. For work with the EBCI community, if approved, a draft of the Council Resolution goes to the researcher first and then back to the respective IRB Chair and then on to Tribal Council for final approval. It is important to note that the Chair of the appropriate IRB must go before Tribal Council as the researcher's advocate. In this process trust is also a key component as the IRB Chair is, to a large degree, putting their personal reputation at stake in advocating for an outside researcher to Tribal Council and the community at large.

Scheduling to speak at a Tribal Council meeting can be different since it only meets once per month. The number of IRB applications EBCI receives vary from year to year but from start to finish, the Tribal approval process can be time intensive, and researchers should expect it to take between three to six months. We recommend that researchers first contact the Chair or an IRB member to make sure that their project would be appropriate. Often the Chair or member will offer some guidance to the researcher regarding the importance of the topic and/or contacts in the Tribe who are invested in the issue. Generally, we suggest that researchers work closely and early on with an appropriate Tribal agency or program so they can partner, consult, and advocate for the project. The EBCI is organized into various Tribal offices, each with specific purviews and

responsibilities. It is helpful to gain the support of an appropriate Tribal agency or program, whose staff can advocate for a project seen as beneficial to their work, and by extension, the community.

To meaningfully engage a Tribal community in research, it takes time, so it is important to plan accordingly in developing your project's timeline (Goins et al., 2011). Below are aspects to the approval timeline that are customary with EBCI.

- Allowing sufficient time to learn about the Tribe regarding issues that are relevant to the project, which often helps identify potential stakeholders and partners.
- Discussions with those who would be most directly impacted by the project. Plan to meet with community members and representatives in community clubs, churches, schools, and other places where people are comfortable in gathering.
- Those serving on IRBs have multiple commitments and scheduling to have a full quorum can be problematic. Also, a Tribal Council meeting may be cancelled.
- For subsequent amendments and re-approvals and require Tribal Council resolutions, scheduling for sessions and time to speak must be done well in advance.

Community is a cultural value so the emphasis on community cannot be taken lightly. You will want to consider engaging in partnerships with community-based organizations or other type of entities depending on your project. A list of EBCI entities that may be considered for this purpose are listed in Table 2.

We also advise potential researchers to check their egos at the door, specifically, the Tribal council door (Lefler & Gleach, 2002). EBCI and other Tribes have experienced years of well-intentioned and some not so well-intentioned researchers who impose their ideas and values on the community, which might not align with those of the people. Substantial time and energy must first

be invested in getting to know the community, culture, language, and history to allow trust in building a positive and lasting relationship.

Table 2. Eastern Band of Cherokee Indian Community Entities for Partnering
Community clubs
Youth organizations or schools
Elder organizations
Women/men groups
Tribal Boards
Health Board
Planning Board
Business Committee
School Board
Health care facilities/entities
Tribal Council
Tribal Executive Branch

Other elements of research to consider include the involvement of Native students in higher education. We must model those protocols that encourage a relationship of trust with Tribal communities and value Native voices, but not exploit them. It is important to make sure we have opportunities for hands-on learning that reflect cultural appropriateness and have real meaning for students. For example, work should highlight the importance of Traditional Knowledge such as the culturally-based behavioral health treatment approaches, providing culturally-relevant information for students in pursuit of health careers and public lectures with culture and language at the core of discussions. However, it is important to be sensitive in not exposing information considered too sacred for publication.

Vine Deloria provides great advice for us. To better relate to Traditional Knowledge and broaden our understanding of how we are connected to all things, we can best understand through the epistemologies and ways of doing through Indigenous language and practices. Deloria knew

this as well. He begins in his book *Metaphysics of Modern Existence*, “The fundamental factor that keeps Indians and non-Indians from communicating is that they are speaking about two entirely different perceptions of the world” (Deloria, 1979, p. vii). His elaboration of this is fundamental in how we come to know Native science and how it can make for realistic application in our work as health care providers and environmental conservators – two fields that for many in the Western academy see as distantly related at best. He continues,

In a white man’s world, knowledge is a matter of memorizing theories, dates, lists of kings and presidents, the table of chemical elements, and many other things not encountered in the course of a day’s work. Knowledge seems to be divorced from experience. Even religion is a process of memorizing creeds, catechisms, doctrines, and dogmas – general principles that never seem to catch the essence of human existence. No matter how well educated an Indian may become, he or she also suspects that Western culture is not an adequate representation of reality. . . the trick is somehow to relate what one feels with what one is taught to think (Deloria, 1979, pp. vii-viii).

As often mentors and advisors to Native students, we are compelled to be reminded of his words and make sure these are things we are conscious of in working with our students and communities.

Conclusion

Even some academics who identify as Native, who are intensely driven to career fulfillment and notoriety, have little regard for the needs and/or wishes of Tribal communities. Instead, they feel it is their agenda that takes priority, and they rationalize that communities may not understand or know what they need. We urge researchers to re-evaluate their heart and spirit, reconciling that agenda to address only the wants and needs of the Tribal community. It is expected by the IRB

and Tribal Council members that researchers whose research has received approval, will fully comply with Tribal expectations that reflect the goals of sovereignty and self-determination.

Kituwah Elders have discussed what could be called “colonizing behavior,” which includes aggressiveness, selfishness, and self-promotion as behavior that was not that of a human being. We must trust those communities that have been historically underserved, exploited, and discriminated against to know best what their needs are and to first and foremost provide service to them. If we get angry with people for them not wanting to allow esoteric research, then we must examine our own hearts and minds (the same word in most Tribal languages) and seek to find what it is that most fulfills us. It is more important for researchers to adopt a sense of humility and service to those communities in which they work. Most academics are innately curious but being overly ego-invested can negatively impact working in Tribal communities. If we are people who have been socialized by Western academies just to accumulate knowledge, we have missed the mark. We are much better served to keep our egos in check and seek to obtain wisdom and the friendship and love of each other – this is way we can be of most service and uphold the integrity of sovereign nations.

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