Tools for Tribal Leaders: Building Research Infrastructure Efficiently

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Collaborative Research Center for American Indian Health (CRCAIH)

• Formed in September 2012 with a grant from the National Institute of Minority Health and Health Disparities

• Sanford Research in Sioux Falls, South Dakota

• Assists tribes (in MN, ND, & SD) and supports researchers to build relationships to plan and conduct tribally-led research on American Indian health disparities

• Mentors tribes in all aspects of research through various cores and divisions
Aims of Presentation

• Outline contents of:
  • The CRCAIH Tribal Institutional Review Board (IRB) Toolkit
    • History on development
    • Ways it can be used to fit within your tribal nation
  • The CRCAIH Research Data Management Toolkit
  • The CRCAIH Research Data Management Toolkit – Version II
    • Updated version
CRCAIH Tribal IRB Toolkit

Who Can Use It?

- Tribal nations that want to develop an IRB or research review board
- Existing tribal IRBs
- Entities that review research in addition to other responsibilities, such as a tribal council, tribal college, tribal historic and preservation office, or urban organization
CRCAIH Tribal IRB Toolkit

How To Use It?

• Contains tools and tips for starting a Tribal IRB

• Recommended that on 1st read, users explore all components in alphabetical order (sections A-E)

• In the electronic version of the toolkit (jump drive made available for session attendees) all files and subfolders are listed in numerical order
CRCAIH Tribal IRB Toolkit

Why Use It?

• Tools and methods *tailored* for AI/AN Tribal IRBs can facilitate the development and improvement of new and existing Tribal IRBs

• No need to “reinvent the wheel,” this tool is intended to serve as a resource that offers practical tools & guidance

• CRCAIH tools and templates can serve the needs of other Indigenous Nations developing IRBs or other committees responsible for ethical review of tribal research
Starting a Tribal IRB

• Obtaining Tribal Approval
• Naming Your Tribal IRB
• Developing Policies and Procedures
• Selection and Recruitment of IRB Members
• Orientation and Training for IRB Members
IRB Administration Tools

• Submission Process Flow Charts

• Investigator Submission Forms

• Pre-Review Tools

• Letter Templates

• Review Process Tools
Research Review Checklists

• Designed to be used by Tribal IRB members, or individuals performing the ethical review of research

• Incorporate both federal guidelines for the review of human subjects’ research as well as guidelines to ensure community protections for tribal nations.

• Includes Initial Review, Continuation Review, Publications Review, Informed Consent, Research with Pregnant Women
CRCAIH IRB Toolkit

- Available for free download at [www.crcaih.org/training-and-resources](http://www.crcaih.org/training-and-resources)

- Numbers do not reflect the printed toolkits distributed

**Website Downloads**

- 2016: 107
- 2017: 62
- 2018: 33
- 2019: 20
Evaluations of Tribal IRB Toolkit

• Downloaded the most by
  • Researchers
  • Research Review Board Members

• Most people found it “very helpful”

• Positives about the toolkit
  • Checklists and forms
  • Easy access
  • Plain language
CRCAIH Research Data Management Toolkit

- Released in 2016

- The main objective is to highlight methods for tribal nations to acquire data from researchers and store data in a way that promotes secondary data use

- Created by CRCAIH staff and Tribal Partners
CRCAIH Research Data Management Toolkit

Who, How & Why?

• This toolkit can benefit AI/AN tribal nations, Indigenous nations, and those interested in research data management

• Offers practical tools and guidance for tribal research data management, though other aspects may also apply to management of other types of data (e.g. data collected for clinical or surveillance purposes)

• We encourage users to review the materials and guidance in the toolkit to identify areas that resonate with the research data management needs of their nations
CRCAIH Research Data Management Toolkit

Contents include:

• Importance of Research Data Management

• Starting a Research Data Storage Process
  • Overview of Maintaining Research Data
  • What You Need to Know About Research Data

• Data Return
  • Importance of Data Return
  • Data Return Process
    • Returned Data
    • Format of Returned Data
    • Timeline of Data Return

• Data Storage
  • Data Access and Security
  • Location
  • Data Backup
  • File/Folder Naming Convention
CRCAIH Research Data Management Toolkit

Contents include:

**Secondary Data Analysis**
- Identifying Useful Data
- Regulatory Concerns
- Uses for Prior Research Data
- Software for Data Analysis

**Creating a Data Management Plan**
- Research Data
- Data Return
- Data Storage
- Secondary Data Analysis
Research Data Management Toolkit Version 1 Use

• Available for free download at www.crcaih.org/training-and-resources

• Numbers do not reflect the printed toolkits distributed
Evaluation

• Tribal Research Review Board Members were main users

• Most rated it as “helpful”

• People rated this as more overwhelming to understand than the IRB toolkit

• People wanted more info on tribal sovereignty and how it affects data management
Research Data Management Toolkit – Version 2

• Version 1 was found to have gaps in information
  • Data sharing – use by tribe & researchers
  • Lifecycle of data (primary & secondary)
  • Data dissemination – use by tribe & researchers

• Contains more relevant information for tribal nations, such as:
  • Specific examples of Research Data Management Procedures
  • Templates of Data Use Agreements
  • Data timeline guidelines throughout the duration of a research project
  • Documents that Tribal IRBs currently use

• Version 2 will be available late summer 2019
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