

American Indian Adult Tobacco Survey

Getting Started: Obtaining Permissions and Groundwork

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Course Objectives

At the end of this course the participant will be able to:

1. Generate tribal buy-in and permissions
2. Identify potential partners
3. Understand and seek IRB permissions
4. Plan the fielding of the AI ATS and;
5. Implement the AI ATS



1. Getting Permission/Securing Buy-In

1. Understanding and acknowledging sovereignty
2. Collaborating with Tribal Leaders
3. Informing/Collaborating with the Community
4. Continued involvement in the Tribal Community



Collaborating with Tribal Leaders

1. Asking for PERMISSION to do the survey
2. It is imperative to make sure Tribal Leaders have a CLEAR understanding of the project
 - Cultural appropriateness
 - Background
 - Purpose
 - Procedures
 - How the community will benefit



Informing/Collaborating with the Community

This can be done by:

1. Presentations at community meetings
2. Articles in Tribal and clinic newsletters
3. Work with community gatekeepers



Continued Involvement in the Community

1. Bi-monthly phone calls
2. Presentations for Tribal Councils and the community
3. Placing regular articles in Tribal Newspapers
4. Providing information on Tribal Websites
5. Staffing informational booths and community events



State Responsibilities Prior to Implementing an AI ATS

1. Identify & develop strong tribal partnerships.
2. Obtain formal tribal and IRB approval prior to ground work.
3. Develop a data sharing agreement with the tribe
4. Work with tribal partners to select supplemental questions best suited to the community.
5. Select appropriate contractors with the knowledge, skills, and abilities to navigate tribal systems and maintain the rigorous protocol required by population-based research.
6. Utilize the CDC implementation manual developed for this survey.



Tribal Responsibilities Prior to Implementing an AI ATS

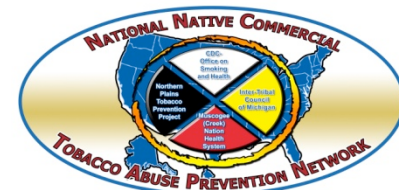
1. Identify & leverage adequate funding to implement the survey from planning to completion of a final report.
2. Keep in mind the expenses of putting the data to action following the receipt of survey data.
3. Identify & develop epidemiology support (IHS funded tribal epi-centers, tribal support centers).
4. Selection of tribal supplemental questions
5. Consider tribal resources for data handling when final data sets are obtained.



Approval Process

2. Tribal approval
 1. Every tribal system is unique.
 2. Communication with tribal health and/ or governing health committee.
 2. Approval from the elected committee frequently a prerequisite of approval from the governing council.
 3. Strong community buy-in will increase data to action.

3. IRB approval
 1. IRB Tribe/ Non IRB Tribe.
 2. IHS IRB approval recommended courtesy.



IRB Submission and Approval

“ An Institutional Review Board (IRB) reviews study protocols to ensure that researchers and study investigators comply with the standards that have been established for the protection of human subjects.”

Office for Human Research Protections:

<http://www.hhs.gov/ohrp/policy/index.html>



IRB Submission and Approval

2. Some Tribes already have an established IRB
3. If a Tribe does not have an IRB you can request one from another institution such as the IHS
4. Project Coordinator must work with the Tribe to determine which organization will provide this approval
5. **START THE PROCESS EARLY**



Adding Supplemental Questions

1. Excellent opportunity to demonstrate responsiveness to tribal concerns. Where does the tribe need additional data?
2. Review the menu of supplemental questions provided with the implementation manual.
3. Review questions from surveys with systematic question evaluation procedures.
4. Refer to CDC Epi and the Question Appraisal System (RTI publication) for the development of new questions.



Question Appraisal System

Provides a checklist of eight possible problem types and many subtypes, with examples

1. **Reading:** possible problems that an interviewer may have reading a question
 - For example, because of missing or unclear instructions
2. **Instructions:** from respondent's point of view
3. **Clarity:** intent or meaning
4. **Assumptions:** appropriateness, consistent behavior
5. **Knowledge/memory**
6. **Sensitivity/bias**
7. **Response categories**
8. **Other:** meets purpose, order



Implementation Planning

1. Data Sharing Agreements
2. Establishing Protocols
3. Recruitment and Hiring Interviewers
4. Determining Locations for Conducting the Survey
5. Maintaining Confidentiality and Security



Data Sharing Agreements

1. Protect data and information generated by research
2. Significant for American Indian populations because of tribal sovereignty and past misuse of data
3. Insure all parties understand privacy issues, data ownership, and dissemination issues



Sampling/Frame Size

1. Goal is ensuring the findings from the survey can be generalized to the population
2. Random sampling: every adult in the tribal community has a chance of being chosen
3. Need to plan who you will work with to get your random sample
4. Challenges to determining the sampling frame (ie. Out of date tribal enrollment lists)



Establishing Protocols

1. To conduct a valid AI ATS you must establish protocols
2. Early development of protocols and procedures will provide a framework for a successful survey



Establishing a Strong Interview Team

1. AI-ATS interviewers should be selected from the communities from which the data will be taken.
2. The role of the interviewer in the successful completion of the AI ATS is unparalleled to state and national level surveillance.
3. Interviewers should have experience with implementing a systematic protocol.
4. AATCHB interviewers had experience with census 2000, voter registration, tribal census, and medical interviewing.
5. Interviewers assisted identifying unreachable persons from the master sample frame.



Survey Location

1. AI ATS developed as a face-to-face survey
2. Need to consider safety and privacy for both the interviewer and respondent
3. Consider respondents home or alternate locations (clinic, community center, park, etc.)



Confidentiality and Security

1. Personal information should be secured at all times
2. No identifying information placed on surveys
3. All project staff should sign confidentiality agreements
4. Make lock boxes available for interviewers
5. Locked file drawer should be available for master lists, completed surveys, signed consent forms, receipts of compensation etc. (Only supervisor should have the key)
6. Information must be shredded after



Budgeting for the AI ATS

1. Implementation Manual Page 44

- Personnel Salaries
- Respondent incentives/compensation
- Interviewer incentive/compensation
- Cost for printing, software, postage, general offices supplies and travel reimbursement
- Costs for meeting facilities for training



Unforeseen Circumstances

1. Interviewer supervisor should be prepared to solve most challenges
2. Interviewers should always have access to one person on the ATS project staff who can make final decisions should issues arise.

