

The Native American Research Centers for Health (NARCH): Success and Challenges in the First Fifteen Years

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The Beginning

Nearly twenty years ago, Dr. Phillip Smith and Mr. Leo Nolan from the Indian Health Service (IHS) and Dr. Clifton Poodry from the National Institutes of Health (NIH) met to consider issues of research in Indian Country. This brief encounter resulted in a seminar of both American Indian/Alaska Native (AI/AN) researchers and Non-Native researchers to develop a proposal to jointly sponsor grants for proposed research projects of health that would benefit AI/AN tribes. This initial grant of approximately \$3 million has grown to over 60 grants representing over \$68 million with contributions from thirteen NIH Institute Centers (IC) to support over 700 AI/AN students and faculty researchers.

The Future

IHS recommends the NIH Institute Centers (IC) build on the success of the first fifteen years and continue to provide adequate and appropriate resources to support AI/AN Tribes to design, implement and analyze data from research conducted in Indian Country.

WHAT WE FOUND

- NARCH stakeholders value the program and express strong desire to see continued progress toward meeting research program objectives.
- Multiple NARCHs report having significantly improved internal grant writing and management capacity over multiple NARCH cycles: Ten of grantees have successfully obtained program grants in multiple cycles.
- More than half of the NARCHs report having developed more collaborative and increasingly successful relationships with Research Intensive Organizations (RIO).
- Through the implementation of NARCH, Tribal Organizations (TO) have obtained Federal wide Assurance for the Protection of Human Subjects (FWA) approval from Office for Human Research Protections (OHRP).
- NARCH has provided opportunities for professional publications and presentations at research professional conferences.
- The education and research efforts conducted through NARCH have been successful in Tribal Colleges and Universities (TCU) gaining accreditation of undergraduate degrees that will increase the number of AI/AN students entering Science, Technological, Engineering and Mathematics (STEM) disciplines.

NARCH HAS IMPROVED HEALTH CARE FOR AI/AN THROUGH-

Preventing, treating, managing disease:

- Confirmed Hepatitis A and B, HiB, Rotavirus, pneumococcal vaccine effectiveness; and
- Expanded understanding of Rheumatic Disease and Autoantibodies in Tribal members by analyzing sera from AI/AN patients with unidentified autoantibody specificities through patients that showed reactivity to traditional rheumatic disease autoantigens.

Discovering lifesaving interventions:

- Discovered that electrolyte re-hydration fluids (e.g., Pedialyte) saved the lives of countless AI/AN babies (gastro-enteritis was the #1 killer of Navajo infants), and now babies worldwide.

Leading the way in health delivery models:

- Established the foundation for use of AI/AN lay health workers to deliver medical care; and
- Pioneered the use of AI/AN Nurse Practitioners, Nurse Midwives, Physician Assistants, Pharmacist-Clinicians mental health technicians in the delivery of medical care.

Introduction

This summary of the Native American Research Centers for Health (NARCH) program supported by the Indian Health Service (IHS) and the National Institutes of Health (NIH), will focus on two process evaluations in the development of innovative approaches to conducting health research and delivery in Indian Country.

The purposes of the NARCH initiative are:

- To encourage competitive research linked to the health priorities of the AI/AN organizations and to reducing health disparities.
- To increase the capacity of both AI/AN organizations and research-intensive institutions to work in partnership to reduce distrust by AI/AN communities and people toward research.
- To develop a cadre of scientists and health professionals engaged in AIAN health research, within and outside those communities, who will be competitive in securing NIH funding.

The NARCH program, in operation since 2000, supports partnerships between American Indian/Alaska Native (AI/AN) Tribes or Tribally-based organizations and institutions that conduct intensive biomedical, behavioral, or health services research. The NARCH program promotes opportunities for conducting academic-level research, providing research training and development for students, faculty members, and Tribal members to meet the health research needs of communities. The NARCH also supports the development of research capacity with the long-term goal of reducing health disparities in AI/AN communities.

The NIH began NARCH funding in FY 2000 and as of 2016, eight NARCH funding cycles have been awarded with each award cycle providing financial support for four to five years with award timeframes overlapping, and some grantees receiving more than one award.¹ Since 2000, over twenty-eight different Tribes and/or Tribal organizations (TO) have received NARCH awards that have collaborated on more than 80 research driven project with over 200 AI/AN Tribes.

The Background section describes a brief history of research in Indian Country and the development of the NARCH program. The Findings Section describes some notable NARCH successes followed by two evaluation studies of the program for the periods 2000-2008 and 2009 - 2014. The results of these studies support the finding that this ‘demonstration or pilot’ initiative to bring research to Indian Country was an effective use and impact of funding through identified major milestones and lessons learned.

Embedded throughout the report are observations on what the research capacity building in tribal organizations looks like, how grantees have learned to manage research budgets, work with limited funds, write progress reports, publications and follow IHS and NIH procedures.

Background

RESEARCH IN INDIAN COUNTRY

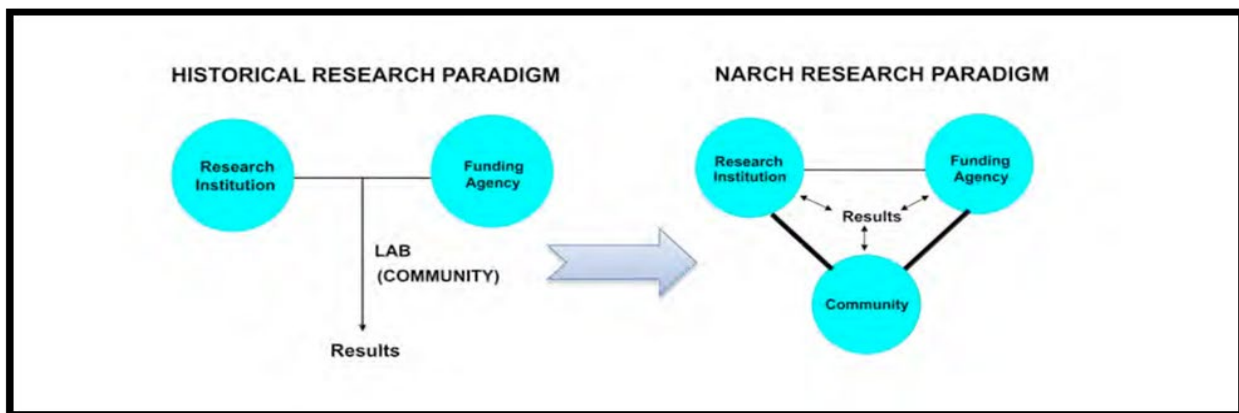
Research in any form conducted within Indian communities is often confronted with a lack of trust and credibility resulting from generations of nonparticipation in the research process and a history of dishonest research practices in conducting research in AI/AN communities (Warne, D. 2006). Yet, the history of research with/in AI/AN communities includes important advances with respect to specific topics (e.g., vaccines, diabetes) and research approaches (e.g., community-based participatory research).

¹ The NARCH initiative supports partnerships between Federally recognized AI/AN Tribes, Tribal organizations (including national and area Indian health boards, and Tribal colleges (TCU) meeting the definition of a Tribal organization (TO) as defined by 25 U.S.C. 1603(d) or (e)) and institutions that conduct intensive academic-level biomedical, behavioral and health services research that comply with the requirements for research integrity, 42 CFR 50

Instances of egregious ethics violations, however, tend to dominate the narratives about tribal research both within and outside of tribal communities. For example, the Nutritional Studies in Residential Schools in Canada during the 1940's, the Study of Alcohol Abuse in Barrow, Alaska during the 1980's, and studies of Havasupai bio specimens in Arizona during the early 2000's are three frequently cited examples of research harms that often drive present-day conversations about tribal research to start from a place of fear.²

Dr. Don Warne illustrates below how 'western' research integrates with NARCH. He illustrates how the striking difference that NARCH research embodies is a 'participatory' approach where the communities and/or individuals and the funding agency help identify and enhance existing mechanisms or develop new research and training programs based upon AI/AN tribal leadership and community guidance.

Figure 1: Research Paradigm in Two Worlds



Source: Diagram adapted from Don Warne, MD, MPH

When NARCH was launched in FY 2000, it was intended that IHS and NIH funds be made available to support scientifically meritorious research projects approved and initiated by Tribes and supported projects designed to increase the research skills and numbers of AI/AN science students and researchers. AI/AN tribes recognized that research is a critical driver for a healthy community within a research agency or organization. However, despite its importance, AI/AN researchers do not have a clear answer to a question one Research Intensive Organization (RIO) faculty asked – “What are the best developmental activities my rising researchers can complete to develop a particular skill in research?” Thus, the competencies needed to demonstrate leadership in research among AI/AN have yet to be developed. The information collected and displayed through this summary may help shed light on this important question.

A Brief History of NARCH

In 1999, the IHS and NIH - National Institute of General Medical Sciences (NIGMS) jointly hosted a roundtable that focused on “American Indian Research Training Needs” where AI/AN research scientists from Indian Country participated. The intent of this gathering was to share the needs and concerns of AI/AN scientists regarding biomedical research and to develop recommendations to improve existing

² The results of a recent ethical misconduct case with the Havasupai tribe where blood samples were in multiple research projects that were far afield of the study purpose within the informed consent further underscore the potential incongruence between AI/AN expectations of research and commonly accepted research practices with biological specimens (Whitener RJ, 2010).

mechanisms for research and training that would be based on the advice and guidance of AI/AN leadership. Various representatives from IHS and NIH attended to hear the final recommendations and considered them as the NARCH program was developed. The roundtable discussion focused on four items: 1) issues of credibility with AI/AN community; 2) needs of new basic science investigators; 3) medical doctors and professionals who want to do research; and 4) encouraging and engaging AI/AN students (NIH & IHS, 1999).

It was during this early formative process that the recommendations of the roundtable for the NARCH program established three major aims: 1) gaining a better understanding of strengths and resiliency factors that may reduce health disparities; 2) reducing mistrust and strengthening partnerships between AI/AN communities and academic/research-intensive institutions to increase community engagement in health research and; 3) supporting the training and development of AI/AN scientists and health research professionals.

A NARCH has general research expectations for the conduct of faculty members and many specific requirements governing the conduct of research essential to encourage an atmosphere of mutual respect, collegiality, fairness and trust. Overall, a NARCH is an entity that receives grant funding from the NIH, and in the early years of NARCH, IHS provided funds and managed all grants. Eligible NARCH organizations must be one of the following: a federally recognized tribe, TO or Tribally authorized Indian Health Board that has formed a partnership with a RIO, and with the federally recognized tribe/tribal organization wanting to conduct high quality research that will be relevant to the health needs of AI/AN. Throughout the lifespan of NARCH, subsequent funding opportunity announcements focused on supporting research training activities which had to be included as part of any application resulting in IHS working with established researchers to develop and encourage NARCH applications from across Indian Country.

The NARCH proposals require well-designed robust evaluation plans to demonstrate that useful knowledge gained, as many researchers (e.g., health care administrators) had limited evaluation knowledge and skills. The IHS and NIH provided Technical Assistance (TA) for some applicants' research proposals to include such an evaluation component. IHS and NIH also understood that NARCH funding opportunities would focus on innovations that would move knowledge into action in the context of research leadership, management and evaluation. Overall, the grant mechanism funded fifteen grantees for multiple projects from 2000-2008. Due to the historical lack of involvement in formal health research, the nature of research projects funded, and internal research capacities of the grantees, it was not possible to identify a definitive set of metrics by which all grantees could be compared. Each project was assessed as broadly as possible to gain a perspective using open-ended interview protocols that allowed flexibility to accommodate varying contexts surrounding each representative organization and the grantees experience with NARCH.

In 2017, NIH and IHS signed a Memorandum of Understanding (MOU) that begins the transition process of NARCH Administration and Management from IHS to NIH (for NARCH IX and future NARCH funding). This is a major milestone for NIH to work directly with AI/AN Tribes to award program funds and to bring relevant research issues/policies to tribes for consultation and respond to requests for consultation through specified processes and meeting specified timelines as described in the NIH Tribal Consultation Policy.

Evaluation Studies

FIRST STUDY: 1999-2009

In 2008, the Robert Wood Johnson Center for Health Policy was engaged by IHS and the Department of Health and Human Services (HHS) Office of Minority Health (OMH) to provide a preliminary qualitative examination of the impact of NARCH funding for AI/AN grantees. This assessment was accomplished through interviews with IHS, NIH, Stakeholders and NARCH grantees on the current state regarding each grantee's progress with the program, its operation, grants management activities and collaborative work with RIO. The stakeholders included those involved in every aspect of research and in the AI/AN community such as representatives from RIOs, individuals from both IHS, NIH and the AI/AN research community who have participated as NARCH grant application reviewers, primary investigators (PI) who participated in previous NARCH cycle grants, NARCH project funding partners, and well established representatives of the AI/AN community.

COMMENT FROM STAKEHOLDERS

“It is absolutely clear that tribal organizations have been ill-positioned to compete for NIH research funding, with little understanding of the capacity and expectations associated with that”

The interviews were designed to provide insight into the NARCH process and experience, and help identify the best means of measuring: 1) the impact on research capacity building and 2) the development of a level of trust and participation by the AI/AN community in research. The open-ended assessment interview from a myriad of NARCH stakeholders also identified and developed structure themes for the subsequent interviews with current NARCH grantees. See Appendix A for a more descriptive table of the unique characteristics and experiences that the NARCH grantees shared.

Overall, the assessment, provided insight into the current organization of the NARCH program but did not address questions about the quality or value of the NARCH and/or its effects, nor was it a comprehensive review or audit of individual NARCH grantees and their grants management processes. Instead, it offered perspectives on program progress thus far and provided recommended steps to enhance the program and grantee performance. More so, the assessment identified that the value of research is not merely intuitive, but that it goes well beyond the fact that undergraduate laboratory work encourages graduate work and undergraduate research as in itself is the purest form of both faculty teaching and student learning.

Key Findings

THE STAKEHOLDER PERSPECTIVE

Several themes emerged from the interviews with stakeholders that attest to the hurdles that AI/AN communities and TOs face in applying for NARCH funding and in managing a grant.

- No two NARCHs look alike – identifying metrics to compare progress across NARCHs is challenging given vast difference in organization and research experience.
- Achieving NARCH program goals is important and requires continued focus.
- IHS faces special challenges in administering NARCH grants as it has historically focused on direct services rather than funding research and must seek fragmented funding sources to meet NARCH objectives.
- Evaluation of these programs is important and a more formal evaluation system would be beneficial.

- Most tribes do not have experience with research grants management.
- Most NARCH projects are funded without the amount needed or requested for core administrative grants.
- Measuring true engagement and community participation in setting priorities and conducting research in Indian Country is difficult; and
- Governance of TOs makes a difference in the potential sustainability of specific NARCHs.

THE GRANTEE PERSPECTIVE

Eleven (11) NARCH grantees were interviewed to gain information about their experience with the program, its operation, grant management activities and collaborative work with RIOs. The decision on whom to include in the interview was determined by each NARCH grantee leadership. Some interviews did not include PIs to enable free discussion about challenges in developing RIO partnerships. The findings of these interviews produced relevant examples identified in Appendix A—Table 1 that speaks about NARCHs unique characteristics, experience and progress.

Structure of Second Evaluation

In 2013, IHS, NIH and NARCH Leadership discussed the need to develop an improved system for collection and dissemination of NARCH outcomes. NARCH grantees as well as all stakeholders expressed significant interest for more ongoing program evaluation. The second evaluation included the creation of preliminary questions which were developed based on the understanding that NARCH funding allows grantees and the RIOs work to; examine the strength and resilience factors that reduce disparities and distrust; increase AI/AN and academia health research partnerships; and support training/development of researchers.

SECOND STUDY

In 2014, a NARCH Annual Progress Report database was developed based on discussions between IHS, NIH and NARCH Leadership that created a list of topics and questions. The question formulation process included face-to-face meetings, teleconferences, webinars and emails between the IHS DPER, the NIH NARCH Program Point of Contact, the IHS/OPHS/Division of Epidemiology and Disease Prevention (DEDP) Sr. Epidemiologist, and the NARCH Principal Investigators (PI)/Directors. Ten broad categories of questions emerged, centered on how to measure the impact of the NARCH funding on achieving the overall NARCH goals.

The fifteen NARCH grantees that were receiving funding in calendar year 2013 were contacted to enter data into the 2014 NARCH Annual Progress Report database. Of these 15 NARCHs, 12 completed the request. Each NARCH respondent provided information from the inception of their specific NARCH program. Data collection took place between October 2014 & April 2015. Data were collected on these ten categories: Centers, Centers and Project Leadership, Community & Scientific Advisory Committees, Projects, Associated Students & Faculty, Associated Publications, Associated Institutions, and Open Ended Center Overview Questions. The total number of individuals identified as affiliated with any NARCH project was approximately 722 individuals, of whom over half were Tribal members. The overall outcomes reported were eleven book chapters, and over 180 peer-reviewed publications and over 297 posters and presentations at professional conferences. APPENDIX B provides snapshots of the individual NARCH Program Priorities Framework with Key Findings.

NON-NARCH FUNDED PROJECTS

Non-NARCH projects have also initially encountered challenges on the issues of trust and community level calamities. Patience, flexibility and guidance from External Advisory Committees eventually helped these projects to overcome these challenges. Non-NARCH project data was included in this report to identify ancillary funding of NARCH grantees. For example, a collaboration between an RIO and tribe may have conducted research in Indian Country as a Non-NARCH entity, prior to receiving a NARCH

grant. In this instance, the Non-NARCH research projects provided positive outcomes of one research project that was used as the resources or inputs for a NARCH research project. The evidence that supports the development of research capacity in AI/AN Tribes to reduce health disparities is through Non-NARCH research projects utilizing their regional or local NARCH IRBs to review and approve their NARCH projects. Non-NARCH projects initially encountered challenges on the issues of trust and community level calamities. For example, the Non-NARCH project may have both AI/AN and non-AI/AN researchers on the project, however both share similar baggage, both positive and negative as they engage in research. Thus, it is critical to note that forming research skills also involves unpacking the role of power and privilege in the research arena (Wallerstein N, Duran B., 2006).

All data submitted for Non-NARCH funded projects was only collected about the PI with an aggregate of the Non-NARCH funded project PI tribal status that indicates over half of the positions were filled by persons that were not AI/AN and less than half of the positions were filled by persons that were members of a federally recognized tribe. Research personnel supported with Non-NARCH funds have a myriad of research experience that is mentored to NARCH funded personnel. For example, the most common source of reported Non-NARCH funding by the 18 NARCH grantees who submitted this information is a R01 funded by NIH. Obtaining a Research Project Grant (R01), which is the original and historically oldest grant mechanism used by NIH, is primarily awarded to institutions to support a discrete, specified, circumscribed project to be performed by a PI seeking to establish a research career. The mentorship the Non-NARCHs' provided to NARCH grantees is needed to ensure not only the development of Researchers but also improved outcomes of research.

Lessons Learned

In the early years of NARCH the circumstances surrounding each grantee had a significant impact on its ability to improve research capacity in Indian Country (See APPENDIX C). Although, the attitudinal challenges among AI/AN communities regarding research has been fraught with distrust, resistance, anger, and broken promises, the majority of these grantees were initially funded in the original NARCH grant cycle. These grantees have obtained not only program grants but student/faculty development funding to strengthen their research infrastructure.

Several grantees expressed on-going frustration with their RIO partners. Some of these were resolved as the NARCHs became or adept at managing subcontractor relationships. In some instances, grantees chose to change or expand RIO affiliations in order to better address their needs.

APPENDIX D—Table 3 points out the differences of the complex priorities necessary to oversee and manage research that requires a delicate balance between the needs of patient care with the desire to spur research in AI/AN communities.

Challenges

Despite the progress described above, the current NARCH funding process presents a paradox. Potential grantees are encouraged by IHS and NIH to develop grant proposals for projects tailored to meet their TO and community needs. Yet, the priorities of funding partners do not always correspond to those of potential grantees given the budget constraints and broader agendas or mandates of these agencies (see APPENDIX E). IHS has worked diligently with each funding cycle attempting to match sometimes disparate priorities after resources that are expended by all parties to produce and review lengthy applications. As a result, the level, sources and funding priorities are often unclear with awards delayed while IHS seeks funding sources. The delay in awards often result in insufficient start-up time and the need for obtaining carry-over approvals.

Beginning in FY 2018, the NIH will award and fully administer the NARCH grants directly to Tribes. The IHS will continue to provide support for the NARCH via technical support, participation in the grant reviews, and guidance to NARCH grantees. This is a major accomplishment. In the beginning, not many believed that NIH could have direct ties to Tribes and Tribal communities. Both IHS and NIH recognize the vital importance of research, the new knowledge and application that research creates, the knowledgeable and skilled human resources developed through the process of conducting research, as well as the importance of peer review, which ensures that funded research meets the highest standards of excellence.

Conclusions and Next Steps

NARCH has provided increasing numbers of AI/AN individuals with skills and experience to both understand and conduct research that will impact their communities. AI/AN tribes have become more comfortable with the increasing number of research activities conducted by tribal members. AI/AN research scientists conducting research in AI/AN communities opens dialogue between the two entities as the researcher help set the terms and values of partnership between AI/AN communities and their research collaborators. NARCH grantees have developed the capacity for the development of key personnel, some who are from the tribal community, to conduct research. In addition, the development of AI/AN researchers support the maintenance of improved cultural sensitivity, capacity, coordination, and implementation of research practices.

True to the hope of the visionary founders of the program, NARCH research continues to establish a direct link between quality of care to the service delivery approach or underlying system of care. It is unfortunate that AI/AN communities have been subjected to centuries of decisions by outsiders that affected their health and welfare without the benefit of equal participation in the decision-making process which has thwarted their trust in regards to research. With increasing numbers of AI/AN researchers and Health professionals developing appropriate skills and attitudes to be advocates in reducing distrust, the NARCH can be considered as an important step from distrust to trust. With the increased focus at NIH on Tribal relations with a formal advisory committee and staff, it is anticipated that the NIH will nurture and expand the program with continued technical support from IHS.

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LIST OF TERMS, ACRONYMS & ABBREVIATIONS

<u>Term</u>	<u>Definition</u>
AI/AN	American Indian and Alaska Native
CBPR	Community-Based Participatory Research
DEDP	Division of Epidemiology and Disease Prevention
DPER	Division of Planning, Evaluation and Research
EAC	External Advisory Committee
IHS	Indian Health Service
Indian Country	Any of the many self-governing AI/AN communities throughout the U.S., it includes all land within the limits of any Indian reservation.
NARCH	Native American Research Centers for Health
NIH	National Institutes of Health
NIGMS	National Institute of General Medical Sciences
OPHS	Office of Public Health Support
PI	Principal Investigator
RIO	Research Intensive Organization
TA	Technical Assistance
TCU	Tribal Colleges and Universities
TO	Tribal Organization/Program

APPENDIX A

Table 1: NARCH grantees unique characteristics and experiences

Characteristic	Experience	Illustrative Progress
Agenda Setting	Approaches to agenda setting vary from operating independently from the tribes to encourage and foster community involvement to working with the highest levels of tribal leaders in the selection of the research agenda and priorities.	<ul style="list-style-type: none"> ➤ One grantee stated how they have quarterly phone conversations with tribal members where the TOs present their priorities. ➤ This list of priorities are then shared with all RIOs within the immediate vicinity to determine which RIO are interested in working with the NARCH. ➤ The use and implementation of AI/AN Community and Scientific Advisory Boards to ensure research is related to the needs of the community. ➤ Involvement of tribal health boards and health councils in the review of proposed research projects. ➤ Involving nearby colleges, Tribal Colleges and University and RIOs on research issues identified by a tribe was then set as a priority for research.
Grant Writing & Grants Management	Some grantees already receiving funding from multiple sources were fully capable of writing their own grants. Others required significant TA from IHS, NIH and their RIO.	<ul style="list-style-type: none"> ➤ Some grantees have their own grants management and financial offices while other grantees are part of larger TOs that offer in-kind services to help manage the grants. ➤ The Tribal Epidemiology Centers provided in-kind support of their grant management as the grantee learn the ropes of collaboration with research partners. ➤ Several grantees reported their grant writing and management skills improved over time following their initial NARCH grant submission. ➤ Some grantees reported a lack of their own financing, grants management, contract staff and the need to rely on TOs or RIOs.
Improvements in Technical Assistance (TA)	Several grantees mentioned the increase and improvements in TA, particularly in the area of the application process and reporting instructions, from IHS over time.	<ul style="list-style-type: none"> ➤ All grantees reported some success in developing internal staff and working with tribal leadership based on guidance received from TA to help them better identify and advocate for the community’s health research agenda. ➤ Grantees reported infrastructure support from RIOs over time. Examples of such efforts range from two-year long certificate programs, to annual summer training institutes, to investing in grants management training. Multiple grantees have student development programs that have operated over multiple NARCH cycles.

<p>Distrust of Research</p>	<p>All of the grantees continuously work to reduce the level of distrust of researchers among the AI/AN community by making their research more participatory and community based as well as discussing their priorities and educating their TOs about the value of Community Based Primary Research.</p>	<ul style="list-style-type: none"> ➤ Efforts to reduce distrust of research included multiple presentations within the TOs and the community and educating newly elected tribal leaders. ➤ Grantees disseminated research progress efforts in newsletters. ➤ One grantee implemented a community and scientific advisory board to regularly disseminate information on its research and progress with hopes to engender more support. ➤ A NARCH advisory committee ensures research is related to the needs of their community. ➤ Grantees are committed to reduce distrust in research by “Growing your own” through the development of training and faculty development programs as a strategy for overcoming distrust. ➤ Developing AI/AN researchers that can draw upon both ‘mainstream’ and indigenous methodologies to increase the translation of research into practice in the community.
<p>Limitations in Resources</p>	<p>Many grantees had difficulty in trying to run and manage grants without core funding.</p>	<ul style="list-style-type: none"> ➤ The grantees that did not have existing research programs and diverse funding sources continue to build and sustain existing research capacities over time. These sources include other federal grants, state grants and foundation funds. ➤ Multiple interviewees indicated that they did not see how tribes in Indian Country could possibly participate in the NARCH program without more core support to build research capacity. ➤ Multiple grantees described the use of considerable in-kind contributions from TOs as well as epidemiology centers, to include uncompensated work performed by PIs and other researchers. This was the case for both well-established and the less mature grantees.

APPENDIX B

KEY FINDINGS

The NARCH program priorities key findings are shown in Table 2.

Table 2: NARCH Program Priorities Framework and Key Findings

Framework of the NARCH Program Priorities	Key Findings
Center & Project Leadership	Half of NARCH Center Leadership Personnel are members of a Federally Recognized Tribe.
Community & Scientific Advisory Committees	Over half of NARCH External Advisory Committee members who hold the most number of chair/voting seats are members of a Federally Recognized Tribe.
Projects	More than half of NARCH Centers reported they are meeting expectations in achieving their center wide goal(s).
Associated Students & Faculty	One-third of the NARCH Centers project investigator positions were filled by individuals who are members of a Federally Recognized Tribe.
Associated Publications	Over half of NARCH Publication First Authors are members of a Federally Recognized Tribe.
Associated Institutions	One-fourth of NARCH associated institutions were Minority Serving Institutions and over half of students and faculty at these institutions were members of a Federally Recognized Tribe.
Open Ended Center Overview Questions	Grantees the need for a formal evaluation of all NARCH projects.
Centers	Of the twelve NARCH Centers Leadership Personnel, one center has identified that their primary employer is a Tribal Government.

APPENDIX C

Findings: Meeting NARCH Aims

The following describes brief examples of the Lessons Learned from the NARCH programs that have met the original aims.

AIM I: GAINING A BETTER UNDERSTANDING OF STRENGTHS AND RESILIENCY FACTORS THAT MAY REDUCE HEALTH DISPARITIES.

The value of research is not merely intuitive; it goes well beyond the fact that undergraduate laboratory work encourages graduate work and undergraduate research is in itself the purest form of both faculty teaching and student learning. NARCH has produced significant outcomes from its infancy.

IMPROVED CLINICAL TREATMENT

In 1980, Dr. Mathuram Santosham, from the Johns Hopkins Bloomberg School of Public Health - Center for American Indian Health, obtained IRB consent, with Tribal support through a tribal resolution to conduct a key field trial on White Mountain Apache Reservation that proved the effectiveness of Oral Rehydration Therapy (ORT) to a skeptical medical community. ORT is an effective treatment for diarrhea that has saved over 50 million lives. He was also one of the first researchers to demonstrate the effectiveness of a vaccine against Haemophilus influenzae type b that is now used around the world. His studies with the Apache and Navajo Tribes, were supported with both Non-NARCH and NARCH funds. As a result, the principle of trust behind conducting any form of research was elevated, a cadre of trained Researchers and research leaders were established and the skepticism that tribal leaders once harbored about research gave way to confidence between JHSPH and the Apache and Navajo Tribes.

Student research interns have been involved in all aspects of the Blackfeet Community College NARCH. to create a research culture and biomedical research center focusing on a Stress, Immunity and Disease Research. This study sought to quantitate levels and sources of stress within the Blackfeet community since high levels or prolonged stress directly suppresses immune function, which in turn can increase susceptibility to numerous diseases. Preliminary findings indicate that higher salivary cortisol levels correlated with decreased self-perceived happiness; however, perceived stress and anxiety did not correlate with increased cortisol in the saliva. After blood and saliva testing, there was significant data that supported that people with high salivary cortisol levels were less prone to acute and chronic diseases. Based on these findings, informed interventions to reduce stress will be developed and implemented in the community and biomarkers for stress will be evaluated to measure if the intervention reduced their levels.

In the “Understanding Rheumatic Disease and Autoantibodies in Oklahoma Tribal Members” project, work was aimed to characterize serologic values and specificities for Native American (NA) patients with rheumatic diseases and healthy individuals with and without autoantibodies to develop new diagnostic and prognostic algorithms. This showed differences in the serological markers present in NAs with rheumatic disease as compared to African Americans (AA) or European Americans (EA). Recent studies focused on the characterization of novel autoantibody specificities in NA Systemic Lupus Erythematosus (SLE) patients, the continued analysis of serologic markers and cytokine dysregulation in NA rheumatic diseases and therapeutic differences in NA SLE patients compared to EA and AA matched disease groups to improve disease outcomes. Analysis of 292 NA SLE patients revealed that 16% were positive for Anti-nuclear antibody (ANA) by one assay and negative using another assay. To overcome this problem, a new GenePix 4000B has been purchased and will be assessed upon delivery. Rheumatoid arthritis (RA) disproportionately affects NAs and the serologic presentation of RA is atypical in NA patients. The

standard prognostic markers, rheumatoid factor (RF) and anti-CCP are often absent in NA RA patients and this results in confounding diagnosis, delaying treatment and poor disease outcomes. The potential of certain cytokines (MCP-1, TRAIL, LIF, VEGF-A and APRIL) are currently being investigated as diagnostic markers or therapeutic agents for NA and a manuscript is in preparation. Results from this study shed light on features that may distinguish NA patients with RA and other rheumatic diseases. Study findings support the development of more rapid and accurate diagnosis of NAs with RA. The ability to accurately diagnose NA RA patients could enable earlier treatment and improving the overall health and reducing disease burden. Focus over the next funding period will be implementation of the protein microarrays to identify novel autoantibody specificities present in NA SLE patients.

SUICIDE PREVENTION

In 2006, the White Mountain Apache Tribe along with Johns Hopkins University, Bloomberg School of Public Health used community-based participatory research to examine suicidal behavior and identify a comprehensive set of risks among reservation-based youth. The data collected helped inform targeted prevention and intervention strategies that address these locally identified risk factors.

AIM II: REDUCING MISTRUST AND STRENGTHENING PARTNERSHIPS BETWEEN AI/AN COMMUNITIES AND ACADEMIC/RESEARCH-INTENSIVE INSTITUTIONS TO INCREASE COMMUNITY ENGAGEMENT IN HEALTH RESEARCH

GREATER USE OF SCIENTIFIC DATA

A significant outcome identified from the NARCH implementation is that AI/AN tribes and tribal leaders now utilize data to improve informed decision making processes, take action about shaping the future of their nation, securing funding for community programs, and refining programs currently offered to their people. Overall, NARCH requires a dedicated annual investment of data translation in order to secure research funds from IHS and NIH. .

Some grantees have a supporting epidemiology center that was in place long before the NARCH program. For example, the IHS in collaboration with NIH, have continued to provide funding for the “Haus Maremsum (Good Medicine) Colville Research Center (HMCRC)” project. This project established a data analysis office to build capacity in providing quantitative data analysis and basic training in data collection techniques and practices to Colville health and wellness programs.

INCREASED NUMBER OF INQUIRIES AND APPLICATIONS

Grantees reported tribal involvement in identifying issues in AI/AN communities and prioritizing topics and areas for research focus, although the nature of the communities’ engagement varied. Different approaches taken were taken by grantees in working with tribes in identifying health priorities and setting research agendas, examples include:

- Solicited ideas from within each tribe for research projects that would be valuable to the community and then develop ideas further with RIO partners.
- With some NARCHs, tribal health divisions examined specific health issues, and health needs in the community and then discussed with researchers to see who is interested.
- With, the tribal boards and health council’s remains centrally involved in the review of proposed research projects.

INCREASED RESEARCH CAPACITY

The grantees with less research capacity prior to NARCH implementation now report improved internal capacity despite limitations in funding and other challenges. Developing research job descriptions, identifying roles and responsibilities, and engaging human resources in research infrastructure development has been a significant accomplishment in capacity building. A Tribal Scientific Advisory Board (TSAB) was developed in the Colville Research Center with four subcommittees; Institutional Review Board (IRB), finance, policies and procedures and tribal research agenda. Haus Maremsum (Good Medicine) Colville Research Center (HMCRC) will continue to supply support to the Colville Tribal College in areas of research coursework and this will assist tribal members interested in research careers. Another project that received funding is “A Culturally Adapted Intervention to prevent Diabetes in American Indian Men”. The aims of this project were to conduct focus groups and interviews with adult members of the Colville tribe to implement a culturally informed diabetes prevention program among overweight and obese AI men. The effectiveness of a community-based, culturally informed diabetes prevention intervention was evaluated to assess between group changes in weight, dietary fat and caloric intake, vegetable consumption and physical activity as primary outcomes. Preliminary review of qualitative data obtained from five focus groups with Colville members indicate that behavioral strategies used in the Diabetes Prevention Program (DPP) educational materials are relevant to AI men.

REDUCED MISTRUST WITH INCREASED NUMBERS OF EXTERNAL ADVISORY COMMITTEES

Developing AI/AN researchers to promote opportunities for conducting academic-level research, provide research training and development for AI/AN students, faculty members and Tribal members involve a transformative learning process. The need for Tribes to increase their capacity to manage and conduct research can be supported through an External Advisory Committee (EAC). In 2014, over half of the NARCH Centers had an EAC with members who are from a Federally Recognized Tribe. Grantees also recognize the significance of NARCH EAC members who are not from a Federally Recognized Tribe have a role to play in how trust in research can become a viable asset in Indian Country.

The IHS and NIH provides TA on how the EAC advises the NARCH projects on strategies and research programs which will not only help the AI/AN tribe build their research leadership capacity to manage and conduct research to meet their health research needs, but to also provide support to the Key Center Leadership Personnel to help reduce distrust. Through the EAC, leadership in research provides support and assistance related to contributions of scientific knowledge and applied practices towards the development of Researchers. The EAC also supports community-driven research, Indigenous knowledge and assistance from tribal leaders about research methodologies and models regarding research. Patience and flexibility and guidance from the EAC helped these projects overcome these challenges.

As the number of EACs increased with each funding cycle, leadership in research provided support and assistance related to contributions of scientific knowledge and applied practices towards the researcher development. The EAC supported community-driven research, Indigenous knowledge and assistance from tribal leaders about research methodologies and models regarding research.

The majority of the NARCH EAC members have extensive Tribal administrative experience and personal interest in the NARCH projects and value the use of EAC to select viable projects that are high priority needs for the tribes. One grantee engages an advisory committee with representation from the community that assures research is related to the needs of the community.

AIM III: SUPPORTING THE TRAINING AND DEVELOPMENT OF AI/AN SCIENTISTS AND HEALTH RESEARCH

A partnerships and lifelong learning are fundamental principles within the AI/AN communities that build their trust in a research framework but, to also engage in meeting the research needs of the tribal communities. IHS and NIH recognizes that AI/AN researchers and health professionals must have access to educational resources such as conferences, attending an institution that provides both undergraduate and graduate degrees with a concentration of any form of Culturally-Sensitive health research and access to education that builds critical thinking through inter-professional, cross-sectoral, experiential learning opportunities from foundational through continuing professional development.

INCREASED NUMBER STAFF MEMBERS OF FEDERALLY RECOGNIZED TRIBES

Research leadership is dependent on individuals who have the experience and ability to mentor inquiring minds. In 2014, half of the NARCH Center leadership positions were filled by persons who were members of Federally Recognized Tribes; and, half were filled by persons who were neither a member of a Federally Recognized Tribe, nor an AI/AN.

INCREASED NUMBER NATIVE STUDENTS IN HEALTH RELATED FIELDS

Researchers and health professionals begin their career at the precollege level. AI/AN students who will become research scientists are now laying the foundations to delineate ideas and support collaborations through attendance and presentations at national research conferences, forums and seminars so that research is brought to tribal communities (Manson SM, Buchwald DS, 2007). Enrolled undergraduates were the largest populations who attended a biomedical, health science or research program. The NARCH provides leadership training to AI/AN who will then serve as researchers. The development of a cadre of researchers engaged in biomedical, clinical, behavioral, and health services research stem from leadership who can secure not only NARCH funding, but also non-NARCH funding.

INCREASED NUMBER NATIVE STUDENTS ATTENDING HEALTH RELATED TRAINING, SCHOOLS AND CONFERENCES

The intent to increase the research leadership skills and number of AI/AN science students and research was made available with funding from both IHS and NIH for 691 students and thirty one faculty.

DEVELOPMENT OF IMERISION PROGRAM AT NIH FOR NATIVE STUDENTS

The week-long program at the NIH campus for Native students developed at the suggestion of the NARCH PI's, provides an introduction to a range of researchers at a critical point in their education.

INCREASED NUMBER JOURNAL ARTICLES and NUMBER PRESENTATIONS AT SCIENTIFIC PROGRAMS

Grantees reported that students who have presented at a Biomedical, Health, Science, or Research conference were both master and undergraduate students. Over half of the NARCH students who have participated in a Biomedical, Health, and Science or Research conference were members of a Federally Recognized Tribe.

While the more established NARCH grantees were successful in publishing multiple articles in peer reviewed journals, those less experience continued to focus on building internal research capacity. The number of First Author Journal Articles show that over half of the NARCH grantees reported a total of 163 Journal Articles. About one-third of these Journal Articles authors were members of a Federally Recognize Tribe.

DEVELOPMENT OF CLOSER TIES WITH TRIBAL COLLEGES AND TRIBAL HEALTH DEPARTMENTS

One Tribe associated with a NARCH issued Request for Proposals to more than ten area colleges and universities on research issues that the tribe identified as important. This helped them identify which potential collaborations and partnerships might be successful in both obtaining grants and achieving their research agenda.

APPENDIX D

Second Evaluation Key Findings

STAKEHOLDERS

The stakeholders stated that the challenges for IHS to function as a health service organization while also serving as an academic environment was daunting. Table 3 identifies the differences of the complex priorities necessary to oversee and manage research that requires a delicate balance between the needs of patient care with the desire to spur research in AI/AN communities.

Stakeholders also stated that many health care professionals don't know or fully understand the governing laws and regulations of research yet have to address the sensitivities of potential concerns within the AI/AN community about engaging in research. Therefore, during the initial discussions of where NARCH would reside was determined by IHS and NIH. They both agreed that centralization of NARCH grants management and administration at IHS would work best for several reasons: 1) to better define accountability and where to go to understand expectations and policies; 2) limit fragmented work flow; 3) simplify accounting and cost center management when all debits and credits to study accounts occur under the oversight of a single person or office; and 4) develop infrastructure inclusive of other key administrative personnel.

Table 3: Differences regarding complex research priorities

Understanding the Differences of an Academic research institutions vs. Health service organization	
Academic Research	IHS Service Organization
<ul style="list-style-type: none"> ➤ Focused on bench, basic and animal research ➤ Investigators hired and protected time granted for faculty to engage in research ➤ Research part of the mission ➤ Pre-award and post-award administrative infrastructure in place ➤ Executive-level leadership for research ➤ Sophisticated research accounting and evaluation system ➤ Prevalence of federally sponsored research ➤ Publication of findings expected 	<ul style="list-style-type: none"> ➤ Greater focus on clinical services ➤ Limited resources spread too thin, both within IHS and for NARCH ➤ No protected time for clinicians to pursue research opportunities ➤ Organizational culture does not view research as a priority ➤ Limited administrative infrastructure ➤ Evaluation needs to be a stronger component built into the NARCH program ➤ Less sophisticated approach to establishing the optimal portfolio of research to match strategic objectives

APPENDIX E

Table 4: NARCH Challenges

<p>Lack of adequate core financial support</p>	<ul style="list-style-type: none"> ➤ Many of the grantees who reported having a lack of core financial support have made progress in building research capacity through NARCH funding only with significant in-kind contributions of their TOs and dedicated staff who perform pro bono work for the NARCH. ➤ Grantees as well as stakeholders expressed concern that the funds associated with core grants were very limited. This presents special obstacles for potential grantees with little if any infrastructure support already in place.
<p>Limited staffing options</p>	<ul style="list-style-type: none"> ➤ Grantees with experienced internal staff expressed concern about the ability to sustain their research capacity should only one or two individuals currently affiliated with the program leave. ➤ Sustainability over time for research centers that do not have core funding and limited staffing remains a challenge. ➤ The nature of staff participation is known to affect project outcomes and effectiveness, and several grantees have reported challenges in engaging staff.
<p>Lack of internal expertise and resources</p>	<ul style="list-style-type: none"> ➤ Grantees reported significant progress in developing the internal expertise and resources for both grant writing and management over time, they often mentioned having made multiple unsuccessful applications before achieving grant awards.
<p>Complex application process</p>	<ul style="list-style-type: none"> ➤ Grantees reported the technical assistance being offered by IHS had improved significantly since NARCH I, but nonetheless speculated that without grant writing assistance and ongoing support, less experienced TOs would be unable to successfully compete in the NARCH arena.
<p>Attrition of TO leadership</p>	<ul style="list-style-type: none"> ➤ Political upheaval and sensitivities related to AI/AN research present challenges to grantees both during and after the application process within their own TOs and sometimes with the academic institutions with which they try to partner.
<p>Inexperience in grants management</p>	<ul style="list-style-type: none"> ➤ While some NARCHs with larger TOs (often associated with Indian Health Boards or epidemiology centers) can rely on the experience of others within their larger organization for support in administering grants and developing subcontracts, others must perform all grant activities with their often skeletal staff. In-kind services provided by larger TOs include budgeting, accounting, developing subcontract agreements, billing subcontractors, proposal writing and PI support.
<p>RIO relationships</p>	<ul style="list-style-type: none"> ➤ RIOs with strong centers for AI/AN health sometimes believe they represent the AI/AN community and can view the TOs as rivals or lesser partners given their later entry into the research arena. ➤ TOs have frequent changes in AI/AN leadership as their governance requires resulting in the need for the TOs researchers and NARCH advocates to repeatedly have to educate and gain support for their efforts.