
Introduction

The Essential Concepts: Core Values, Partnership, and Protection

Teshia G. Arambula Solomon, PhD, and
Leslie L. Randall, RN, MPH, BSN

Storytelling is at the core of who we are. It is the way we share information, make connections, find our relationships, learn, and teach. The stories we tell in this book are a reflection of all this, plus gratitude for the gifts we have been given: the opportunity to learn from our community, our partners. In this book we weave the voice of science—objective, distant, factual—and the voice of culture—subjective, close, experiential. We describe historical accounts and speak of our own experiences as Native investigators and the non-Natives who have made an effort to understand the culture and people. We walk in the space between contemporary science and Native tradition regularly in our work, so it is reasonable that we would also do this here. This is one of the greatest benefits of this book: we seek to create a relationship with the reader and weave together what we have learned from academia, our own traditions, and our personal experience as Native investigators.

RATIONALE

The old saying “the road to hell is paved with good intentions” means that sometimes even when we intend to do good, things may not work out the way

we plan. The histories of Indigenous people worldwide are littered with policies and practices of deliberate maltreatment, abuse, and criminal activity in the name of money, power, land, and religion, resulting in the all-too-common outcomes of poverty and poor health. Such acts are easy to condemn and criticize, and it is easy to understand why people are distrustful of government entities and other institutions and research in general.

Less obvious, however, are the problems created and the damage done when we try to be helpful. Presumably there are researchers and scientists who are unethical, fraudulent, and self-promoting, as there are such people in all walks of life. We have been fortunate because the majority of the people we have worked with are good people. They didn't go into health, science, or education to become rich or famous, but rather because of a desire to make a difference in the world, to be of service, and for the simple joy of learning and discovery. Unfortunately, even research done with good intentions has caused harm to individuals and communities.

Research is often something “done” to Native people without full disclosure by the researcher and full understanding and consent of these communities and individuals, rather than something conducted by them and for their benefit. It is not uncommon for researchers to come into a community, conduct a quick research project, and then leave, taking with them data, specimens, and community trust. Approvals to conduct the research are neither sought nor given, and if they are it is often without a complete understanding of purpose and benefit. The results and benefits are not shared, and permission to publish the results or any other information about the community are neither sought nor provided. The consequence of this approach is that Native people have a profound distrust of research, researchers, and the institutions that support them.

Many communities feel they have been over-researched and often there is little-to-no concrete evidence that the community of study has benefited from the research. For example, the Pima people of Arizona have been participants in diabetes research for over 50 years, providing valuable information for the development of pharmaceuticals like angiotensin-converting enzyme (ACE) inhibitors and angiotensin II (AT II) inhibitors to prevent end-stage renal disease. These discoveries have been a gold mine for pharmaceutical manufacturers; however, the death rates for Native American (NA) persons caused by diabetes are still astronomical, and little money or support has been

returned to this community. In 1980, diabetes was the sixth leading cause of death among American Indians and Alaska Natives (AIANs), and in 2006 it was the fourth leading cause of death (CDC 2009). Death rates for the AIAN population (39.6/100,000) are nearly twice the rate of the Non-Hispanic White population (20.4/100,000; CDC 2010a) and for AIAN women, the disparity is even higher (40.7/100,000), nearly twice the rate of the Non-Hispanic White population (17.0/100,000; CDC 2010b). This old model of research is no longer welcome.

This book describes a philosophy and represents the current trend in Native communities of reclaiming power and sovereignty by controlling the research that is conducted in their name and on their lands. Although we only touch on tribal sovereignty and self-governance, there are many reference books and articles that address that issue in depth. Authors such as Deloria and Wilkins expound on the historical, cultural, and legal aspects, while authors such as Peviar and Canby cover the purely legal aspects of Indian law. We present here a model of the “how” with an appreciation of the “why.” We offer a model that is collaborative and in which the community actively participates in the design, development, implementation, and evaluation of the research and benefit economically as well as regarding health outcomes. This philosophy embraces three essential concepts: (1) core values, (2) partnership, and (3) protection, which are intermingled within the larger context of culture.

All research should be consistent with the values of the population of study. Core values of Native communities such as family, respect, honesty, kindness, caring, and sharing should be honored. Research that uses conflicting methodologies may harm individuals and the community and offer no benefit to them. Throughout this book, the authors discuss common values across communities; this is particularly addressed in Joe’s chapter on cultural competency. Cultural values are not always easily observed or expressed. Ignorance of these practices not only can lead to an unsuccessful research endeavor but also may lead to litigation or other ramifications, whereas being knowledgeable about them generally leads to success. The best way to be informed on culture, values, and traditions is to involve the communities of study in the research process. This is achieved through transparency and partnerships.

Throughout the book we use the term *participatory research*, which has come to be the model embraced by Native communities and is exemplified by

the researchers who contributed to this book. A partnership between the researchers and the community should be brokered to the level desired by the community, encompassing all that the term legally and sociologically implies including sharing resources, profits, publication, and other forms of recognition. There should be transparency in all transactions and they should be negotiated with the community of study prior to submission of an application. Any benefits, financial or otherwise, must be shared equitably with the study population and the community. Those who have participated in the production of this book are known as researchers who have abided by the wishes of the community for years, have shared their knowledge of the research with the community, have been to the community to consult with and report back their findings, and are respected by the communities with whom they work, and the majority are Native themselves.

As a result of a history of abuse and neglect, Native communities must protect themselves through self-determination and self-governance. Indigenous knowledge must be protected as one protects those things that are sacred in the major religions, and intellectual property rights must remain with the elders or other knowledge holders within the community. Through the creation and implementation of respectful partnerships, cultural protocols and traditions will be inherently protected and respected. As with all research, individual consent is mandatory. But because Native people may have difficulty with language or reading or simply understanding the culture of research, we must go the extra distance to ensure that consent is truly fully informed. A full and informed consent from individuals and the community may require tactics such as video consent or translation when language and literacy are an issue. It is important to note that the legal language used by most research institutions is often confusing to the participants, and the institutional review board (IRB) forms that protect the research institution may not be sufficient to protect the individual or the community. Confidentiality is also a common protection afforded in health research; however, for Native communities in which populations are particularly small, this issue becomes imperative. Confidentiality, anonymity, and public recognition must be negotiated before presentations or publications are made public. Study participants or community leaders should be co-authors on presentations and publications and should have the opportunity to review and revise. Data sharing, management, and reporting should all be determined *a*

priori and with shared control, with the understanding that most Native communities will assert sovereignty and ownership of all data and that the researchers may not keep copies of data for their own use.

This book grew out of presentations originally given in 2000 as a Continuing Education Institute (CEI) at the 129th Annual Meeting of the American Public Health Association (APHA). Since that time the editors and authors have experienced all that life has to offer, including multiple moves across the country with job changes, retirements, births, hardships, illness, losses, and deaths. We have, however, persevered and are delighted to bring this edition to fruition.

ORGANIZATION

The first half of the book provides a foundational context within which research occurs. Chapter 1 is a brief overview of AIAN history and politics in the United States to give the reader a framework for understanding how history and politics have influenced Native communities and why they are so resistant to and distrustful of research. In Chapter 2 we examine the difficulty in measuring and describing health patterns in Native communities because of data limitations that cloak our problems. Once this foundation of understanding is built, Randall, in Chapter 3, draws upon her extensive career in NA health for an introduction to working with Native communities, the essence of which is relationship building, and highlights briefly various research guidelines developed in other Indigenous communities. Chapter 4 then stresses the importance of understanding the unique cultural foundation of distinct and individual tribal nations. In Chapter 5, Tualii, Quenga, and Samoa introduce the reader to common problems facing Native Hawaiians and Pacific Islanders.

The second half of the book presents examples of research projects in the form of case studies of specific experiences. Hodge and Struthers in Chapter 6 and Tom-Orme in Chapter 7 open our eyes to successful models and methods of working in Native communities, and in Chapter 8 Welty provides living examples. Chapter 9 provides the opposite side of the coin, that is, what happens when things do not go as intended.

Last, we provide guidance in the ethical conduct of research. In Chapter 10 Cook describes a model process for developing research policy, the keystone to

ethical conduct, and Gachupin and Freeman in Chapter 11 review the specifics of research that utilizes biospecimens.

TERMINOLOGY

Determining who is and is not a Native American is a complex issue, and different groups have different positions on how people are described. In general, most Native people want to be referred to by the tribe to which they belong; for example, the Choctaw Nation or the Nimiipuu (Nez Perce). However, we rarely speak about individual communities for all the reasons described in this book and instead usually refer to people in the aggregate. In this book we use the term *Native American* or *American Indian* to describe the Indigenous peoples of Canada, the contiguous United States, Alaska, the Hawaiian islands, and the islands of Guam and American Samoa. American Indians and Alaska Natives are part of 566 federally recognized and more than 100 state-recognized tribal nations (tribes, nations, bands, pueblos, communities, rancherias, and native villages) in the United States, approximately 229 of which are located in Alaska.

Some people use the terms *Indigenous* or *Indian* interchangeably for American Indians or Native Americans. However, *Indigenous* refers to the original peoples of a geographic area; for example, the Indigenous people of New Zealand are the Maori. The term may be used when referring collectively to original peoples of many lands. *Indian* can also be confused for reference to the people of India, but in this book, it's obvious that we are referencing American Indians. Some people may use the term *Indian country* to refer to all the tribal communities across the United States.

Indigenous islanders are often grouped together and termed Native Hawaiian and Other Pacific Islanders or grouped with the Asian population as the Asian/Pacific Islander population. As described in Chapter 5, the term *Native American Islanders* refers to descendants of the original Natives of Hawai'i, Guam, Samoa, or other Pacific Islands.

In Canada, there are three politically and culturally distinct groups that comprise the 1,172,790 Aboriginal peoples of Canada (about 3.3% of the Canadian population): (1) First Nations, (2) Inuit, and (3) Métis. Aboriginal peoples are both the fastest growing and youngest population in Canada, as they experienced a 45% increase in population growth between 1996 and 2006,

compared with an 8% increase for the non-Aboriginal population (Statistics Canada 2008).

SUMMARY

This book was designed for those with good intentions to understand the potential pitfalls and outcomes of even the most well-intentioned research projects. Conducting research in Indian country can be a truly rewarding experience. NA people are generally warm, welcoming, and generous, but conducting research in their communities can be truly challenging, as Native Americans are a proud people with a well-earned distrust of outsiders. Being a Native researcher is not a license to conduct research in any Native community. Even researchers with proven track records and in good standing among NA communities will run into obstacles with their projects. Approval processes can be long, tribal politics can be an impediment, and research sites can be distant.

We hope this book will benefit those who are unfamiliar with Indigenous community research, its history, and politics, particularly those who are responsible for collecting data on the health and well-being of Native people (including academic researchers and public health officials at all levels of government), and that it will serve as a guide and a model for conducting respectful research in all communities. It is our greatest hope that Native communities will benefit from this book, not only through the education of the uninformed but also in building the capacity within their own communities to create a dialogue surrounding the research enterprise, for Native people will only be truly protected when they develop the capacity to direct, fund, and implement their own research, following well-developed research agendas and training high-quality Native researchers.

We also offer a note of caution that simply reading a book does not make one an expert, nor does writing one. If we clearly communicate only one message it is that the researcher must have an intimate understanding of the beliefs, values, and practices of the community of study and must both know and understand the laws of that community before embarking on a course of research. The only way to do that is by investing time in building partnerships with the community government and its people. In fact, that single statement is a perfect example; just as the US government is distal to us as individual US

citizens, so are our tribal governments. Having a relationship with one is not sufficient; you must also have a relationship with both the tribal government and the community it is elected to serve. While tribal governments can vet you and grant you entrée, it is individual Native people who consent to participate. We hope you enjoy the book and wish you the best of luck in joining us to serve our Native brothers and sisters.

REFERENCES

Centers for Disease Control and Prevention. 2009. *National Vital Statistic Report. Vol. 56, Num 10 Table 17 and Table 16*. Available at: http://www.cdc.gov/nchs/data/nvsr/nvsr57/nvsr57_14.pdf. Accessed July 10, 2013.

Centers for Disease Control and Prevention. 2010a. *Health United States, 2009. Table 26*. Available at: <http://www.cdc.gov/nchs/data/hus/hus09.pdf>. Accessed July 10, 2013.

Centers for Disease Control and Prevention. 2010b. *Health, United States, 2009: In Brief—Medical Technology*. Available at: http://www.cdc.gov/nchs/data/hus/hus09_InBrief_MedicalTech.pdf. Accessed July 10, 2013.

Statistics Canada. 2008. *2006 Census, Aboriginal Peoples*. Available at: <http://www12.statcan.gc.ca/census-recensement/2006/rt-td/ap-pa-eng.cfm>. Accessed September 13, 2013.