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Tribally-Driven Participatory Research: State of the practice and potential strategies for the future

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ABSTRACT

This paper discusses current practice of research with and by American Indian tribal governments in the United States. It begins with a brief overview of Community-Based Participatory Research and compares and contrasts its principles and methods with what this paper terms Tribally-Driven Participatory Research. The paper analyzes current challenges and offers concepts for continuing to improve the effectiveness of Tribally-Driven Participatory Research.

Keywords: research policy; tribal governments; community-driven participatory research; American Indian

INTRODUCTION

We begin this paper on Tribally-Driven Participatory Research (TDPR) by describing its roots in Community-Based Participatory Research (CBPR). We then compare and contrast the principles and methods of CBPR with those of TDPR. The current practice of research with and by American Indian tribal governments in the United States is described and current challenges are outlined and concepts and strategies for continuing to improve the effectiveness of Tribally-Driven Participatory Research are outlined.

Community-Based Participatory Research (CBPR)

Development of Community-Based Participatory Research

For more than two decades, increasing numbers of communities, advocacy organizations, government agencies and university centers have promoted an approach to expanding knowledge and improving health and quality of life that builds on the strengths of communities, empowers communities, and produces valid, useful and meaningful results. The core principle of this model is that scientific research needs to involve, throughout the entire process, a full partnership between the researchers and the study-communities (Macaulay et al., 1998; Davis & Reid, 1999; Dignan et al., 1998; Garwick & Auger, 2003; World Health Organization, 2003; Holkup et al., 2004; Letendre & Caine, 2004; Manson et al., 2004; Brown, 2005; Burhansstipanov et al., 2005; Caldwell et al., 2005; Arizona Biomedical Research Commission, 2006; Brugge & Missaghian, 2006; Christopher et al., 2008; Edwards et al., 2008; Nilson et al., 2008). A whole taxonomy for this research model has been developed; however, there is growing consensus around the label Community-Based Participatory Research (CBPR) (Burhansstipanov, 1998; Davis & Reid, 1999; Israel et al., 2001; Fisher & Ball, 2003; Ortiz, 2003; Holkup et al., 2004; Letendre & Caine, 2004; Edwards et al., 2008; Gibson et al., 2008)[1]. Some reviewers suggest the CBPR practice involves collaboration at all stages of research, from planning through implementation and evaluation. Others propose that it need only involve one or two of these elements.

Today some principles of CBPR have been incorporated into federal research guidelines and funding requests (Israel et al., 2001; Holkup et al., 2004; Burhansstipanov et al., 2005; Caldwell et al., 2005; Arizona Biomedical Research Commission, 2006; Brugge & Missaghian, 2006; Buchwald et al., 2006; Strickland, 2006). Numerous researchers have discussed the antecedent theoretical and methodological foundations, acknowledging that many of the core elements have been used for over a century in community organizing as well as participant-observation methodologies (Brugge & Missaghian, 2006; Nilson et al., 2008). Many analysts assign descriptive labels to distinguish core differences between research and CBPR. Research is often characterized by the 'helicopter research' approach in which outside 'experts' come into a community, gather information and leave, (Hodge et al., 2000; Brown, 2005) or 'safari research,' in which outside researchers visit a community, observe, gather limited information and leave with their 'trophies' (data; publications; careers) (Macaulay, 1994; Christopher, 2005). The community neither participates nor benefits.

Federal protections have been in place for individual human subjects in biomedical and behavioral research since the publication of the 1974 Belmont Report of the National Commission for the Protection of Human Subjects (Beauvais, 1999; Model Tribal Research Code, 1999). These protections require informed consent of research participants, maximization of benefits and minimization of harm as well as fair treatment of all individuals (Beauvais, 1999; World Health Organization, 2003). Regulations (Title 45 of the Code of Federal Regulations, Section 46) resulted in the development of Institutional Review Boards in the 1980's within federal agencies and universities to review proposals and ensure compliance with federal requirements (Hodge et al., 2000; Arizona Biomedical Research Commission, 2006; Brugge & Missaghian, 2006). In the past decade, a few federal agencies, primarily those involved in health research, such as the National Institutes for Health, began to adopt the CBPR approach because, despite the protections for individual human subjects, there was increasing recognition that communities also needed to be protected and that

1. Some of the names in the literature for this research model include: Applied Research; Appreciative Inquiry; Community-led Research; Co-operative Research; Culturally Competent Research; Development Action Inquiry; Emancipatory Research; Participatory Action Research; Respectful Research

standard research approaches were not significantly reducing health disparities within the U.S (Israel et al., 2001; Burhansstipanov et al., 2005; Buchwald et al., 2006; Strickland, 2006).

Agency Directors, inspired by a Clinton Administration Policy mandate to achieve results, were made aware of biomedical research 'on' communities that were at best exploitative and, at worst, criminal, began to consider strategies to avoid these problems and lawsuits (Holkup et al., 2004; Manson et al., 2004; Christopher, 2005; Christopher et al., 2008). As a result, CBPR largely has been focused on biomedical, health and behavioral science fields, although practitioners generally acknowledge that the principles of CBPR need to be part of all research that involves and affects not only individuals but communities (Model Tribal Research Code, 1999; Fisher & Ball, 2003; Brugge & Missaghian, 2006). Even so-called basic science, with its focus on the fundamental questions of the physical universe, has begun to incorporate elements of community empowerment in programs in order to increase student recruitment and retention in the science, technology, engineering and math fields (Nilson et al., 2008).

Core Principles of Community-Based Participatory Research

Most of the CBPR literature identifies the same core principles, elements and methods, although the names given to these sometimes differ. The greatest variability occurs concerning the inclusion of 'post-research' elements such as advocacy and implementation. This overview paper cites a number of articles on CBPR development, its core principles and its use in a wide range of projects. CBPR practitioners generally agree on these core principles:

- Recognition of community (not just individual) values and goals as well as the potential for collective harm (Beauvais, 1999; Davis & Reid, 1999; Model Tribal Research Code, 1999; Ortiz, 2003; World Health Organization, 2003; Holkup et al., 2004; Letendre & Caine, 2004; Brown, 2005; Caldwell et al., 2005; Arizona Biomedical Research Commission, 2006).
- Development of full partnerships between institutional researchers and communities that build trusting relationships over time (Beauvais, 1999; Davis & Reid, 1999; Israel et al., 2001; Fisher & Ball, 2003; Garwick & Auger, 2003; Ortiz, 2003; Letendre & Caine, 2004; Burhansstipanov et al., 2005; Christopher et al., 2008; Nilson et al., 2008).
- Community participation in all aspects throughout the entire research process (Macaulay et al., 1998; Davis & Reid, 1999; Israel et al., 2001; Garwick & Auger, 2003; Burhansstipanov et al., 2005; Arizona Biomedical Research Commission, 2006).
- Empowerment of communities by building research capacity (Israel et al., 2001; Letendre & Caine, 2004; Brown, 2005; Caldwell et al., 2005; Arizona Biomedical Research Commission, 2006; Baydala et al., 2006; Brugge & Missaghian, 2006; Teufel-Shone et al., 2006; Salsberg et al., 2007; Edwards et al., 2008).

The basic CBPR elements and processes are built on regulations that protect individual human subjects in federally-sponsored research and mirror the principles for protecting individual human subjects laid out in the Belmont Report:

- **Respect for communities:**
  -obtain informed consent by providing full information and ensuring full comprehension; acknowledge the voluntary nature of participation (Beauvais,1999; Model Tribal Research Code, 1999; Hodge et al., 2000; World Health Organization, 2003; Holkup et al., 2004; Arizona Biomedical Research Commission, 2006; Nilson et al., 2008).
- **Beneficence:**
  -maximize benefits to communities (Davis & Reid, 1999; Stoddart et al., 2000; Ortiz, 2003;

World Health Organization, 2003; Letendre & Caine, 2004; Caldwell et al., 2005; Arizona Biomedical Research Commission, 2006; Baydala et al., 2006; Nilson et al., 2008).

- **Non-maleficence:**
  -do not harm communities (Ortiz, 2003; World Health Organization, 2003; Brown, 2005; Caldwell et al., 2005).
- **Justice:**
  -develop knowledge that benefits communities; treat communities fairly (World Health Organization, 2003; Arizona Biomedical Research Commission, 2006).

Increasingly, practitioners point out that CBPR efforts are much more likely to be sustained because the research results are of value to communities and the research process empowers communities through participation (Macaulay, 1994; Davis & Reid, 1999; Stoddart et al., 2000; Garwick & Auger, 2003; Ortiz, 2003; Holkup et al., 2004; Burhansstipanov et al., 2005; Edwards et al., 2008). Sustainability makes CBPR particularly well-matched to research affecting American Indian tribes in the United States because of the permanence of their status as governments as well as the long-term interests of tribal governments in their land and people (Stubben, 2001; Fisher & Ball, 2002; Manson et al., 2004; Brugge & Missaghian, 2006). This governmental permanence also fits well with the long-term funding approach essential to Tribally-Driven Participatory Research.

Tribally-Driven Participatory Research (TDPR)

CBPR in American Indian Tribal Communities: TDPR

There is a growing body of literature on Community-Based Participatory Research within American Indian tribal communities; many of the team members of the Southwest American Indian Collaborative Network (SAICN) are in the forefront of this research and a number have published on tribally-based participatory research goals and projects (Arizona Biomedical Research Commission, 2006). Researchers and agencies generally acknowledge that valid and empowering research with tribal communities (Tribally-Based Participatory Research) has a great deal in common with the principles and methods of CBPR, primarily the full participation of tribal governments from the earliest stages as well as their empowerment and capacity-building (Burhansstipanov, 1999; Fisher & Ball, 2002; Fisher & Ball, 2003; Burhansstipanov et al., 2005; Christopher et al., 2008).

American Indians, as well as indigenous peoples throughout the world, have conducted research for millennia; in fact, indigenous knowledge gained by observation and experimentation produced much of the world's foodstuffs as well as many medicines that researchers today seek to assess (Nilson et al., 2008). The Science in a Circle© model developed by First Nations in Canada notes that many aboriginal communities consult with elders to find out what is already known in the same way that academic researchers now conduct a literature review (Nilson et al., 2008). [2]

For the last two centuries, tribal communities have been the subject of research by outsiders attempting to gain knowledge about American Indian biology and behavior (Model Tribal Research Code, 1999; Hodge et al., 2000; Garwick & Auger, 2003; Brown, 2005; Christopher, 2005; Christopher et al., 2008; Edwards et al., 2008). Many of these efforts not only gave 'research' a bad name in Indian Country but tragically, most of it did little to empower tribal communities, build capacity or protect intellectual property of American Indians and tribal governments (Beauvais, 1999; Inuit Tapiriit Kanatami, 2003; Brown, 2005; Burhansstipanov et al., 2005; Brugge & Missaghian, 2006). This research

2. Nilson, Suzanne M., Lalita A Bharadwaj, Elder Doug Knockwood, Vince Hill "Science in a Circle© : Forming "Community Links" to Conduct Health Research in Partnership with Communities" Pimatisiwin 6(1):123 – 135.

done by outsiders not only exacerbated mistrust between American Indian communities, federal agencies and universities, but it often produced data and analyses that were invalid (Beauvais, 1999; Model Tribal Research Code, 1999; Caldwell et al., 2005; Christopher, 2005; Christopher et al., 2008). To the extent that mistrust generated by research in the past has made tribes and American Indian people less willing to conduct and participate in research projects today, including clinical trials, the damaging legacy of past research is multiplied (Macaulay, 1994; Burhansstipanov, 1998; Hodge et al., 2000).

On the positive side, there are historical examples of individual researchers and government-funded projects that have succeeded in achieving at least some of the desired results of TBPR, particularly in improving health (Arizona Biomedical Research Commission, 2006). Often cited are the research project on sulfa antibiotic treatment for trachoma (eye infections) in the 1930's with the White Mountain Apache, as well as the clinical trials, championed by Annie Wauneka at Navajo in the 1950's, on isoniazid (INH), which proved effective in treating Tuberculosis (Davis & Reid, 1999). Most successful research of the past incorporated at least some elements of TBPR. Focusing on these empowering aspects of successful research may assist tribes to overcome the negative legacy of the past and to take steps to implement Tribally-Driven Participatory Research (Garwick & Auger, 2003; Christopher et al., 2008).

From Tribally-Based to Tribally-Driven: The Active Power of Tribal Governments

While CBPR core principles are critical to research that produces valid and positive results in tribal communities, there is a major difference, at some level a qualitative difference, between Community-Based and Tribally-Based Participatory Research (TBPR). Unlike other community participants in CBPR, tribal governments are established by law and have governmental authorities to regulate research activities within their jurisdictions (Beauvais, 1999; Stubben, 2001; Fisher & Ball, 2003; Letendre & Caine, 2004; Manson et al., 2004; Caldwell et al., 2005; Arizona Biomedical Research Commission, 2006; Brugge & Missaghian, 2006). Tribal governments, particularly under Self-Determination policies and Self-Governance procedures, can be more than a passive 'base' for research; they can actively control and 'drive' research (Davis & Reid, 1999; Model Tribal Research Code, 1999; Fisher & Ball, 2002). The phrase 'Tribally-Driven Participatory Research' captures a model that is active and controlling, rather than passive (Macaulay, 1994; Burhansstipanov, 1999; Ortiz, 2003; Gibson et al., 2008). TDPR involves research in which tribal governments 'drive' on their own as well as research in which tribal governments invite collaborators on the journey (Burhansstipanov, 1998; Macaulay et al., 1998; Fisher & Ball, 2002; World Health Organization, 2003; Letendre & Caine, 2004). In TDPR, the research direction and destination is determined by the tribal government/driver (Davis & Reid, 1999; Salsberg et al., 2007).

One of the critical research issues discussed extensively in research guidelines developed by the World Health Organization and the federal government of Canada is defining and identifying a "community." CBPR practitioners recognize that the membership and boundaries of particular communities may change over time (World Health Organization, 2003; Brown, 2005; Canadian Institute of Health Research, 2007). In contrast, tribal governments have largely defined authorities and jurisdiction (Brugge & Missaghian, 2006). Unlike most communities, but like most governments, tribal governments conduct their own research and are in an excellent position to build capacity over time (Stubben, 2001; Letendre & Caine, 2004; Brugge & Missaghian, 2006). Tribal governments have the jurisdiction to initiate and control research agendas and, as they determine appropriate, request the assistance and collaboration of agencies and universities (Macaulay et al., 1998; Manson et al., 2004; Nilson et al., 2008). The term Tribally-Driven Participatory Research echoes the similarities in core principles with CBPR while capturing the critical governmental authority of American Indian tribes.

The qualitative difference between CBPR and TDPR is that tribal governments have the authority to codify research requirements in tribal statutes that can be more stringent than federal requirements (Macaulay et al., 1998; Model Tribal Research Code, 1999; Fisher & Ball, 2003; Letendre & Caine, 2004; Brugge & Missaghian, 2006). Tribal governments also can conduct compliance assurance and enforcement if researchers do not comply with their laws (Model Tribal Research Code, 1999; Fisher & Ball, 2002). There is a substantive difference between asking researchers to comply with community values and traditions and potentially taking them to court, issuing fines or taking other enforcement actions (e.g., injunctions; banning), if they do not (Model Tribal Research Code, 1999). Tribal governments in the U.S. are in a position to fully realize the goals of CBPR on a day-to-day basis and provide leadership in making full participatory research the national standard.

Tribally Initiated Research: Internal, contractual and collaborative

Tribal governments regularly conduct a wide-range of research and most tribes have substantial experience in identifying research needs, gathering and analyzing data and using information to shape decisions. Tribes often conduct their own research projects internally, using staff and even volunteers (Hodge et al., 2000; Stoddart et al., 2000; Fisher & Ball, 2003; Inuit Tapiriit Kanatami, 2003). In some cases, tribal governments and their departments may choose to use outside contractors to gather and analyze information because there is a lack of local specific expertise or it is more efficient to use contractors rather than hiring permanent employees for short-term, focused projects (Macaulay et al., 1998; Inuit Tapiriit Kanatami, 2003; Caldwell et al., 2005; Buchwald et al., 2006; Edwards et al., 2008).

In some cases, tribal departments may chose to contract for research and analysis in order to increase the perception (or reality) of objectivity regarding outcomes (Fisher & Ball, 2003). These contractual relationships may be with private consulting firms or universities, and often face challenges similar to those found in CBPR. When outside researchers are brought in to a tribally-generated research project, there need to be conditions for respectful dialogue between the researchers and the tribal community (Baydala et al., 2006; Edwards et al., 2008). In research projects in which there may be conflict about the issues within the community, researchers ideally act as catalysts and facilitators to assist the community to understand the problems and develop solutions (Gibson et al., 2008).

Tribal governments increasingly strive to incorporate the benefits of CBPR into contractual research and projects, particularly the hiring and training of tribal members and tribal ownership of any equipment or software purchased as part of the contracts (Manson et al., 2004; Arizona Biomedical Research Commission, 2006; Baydala et al., 2006). However, one of the ways tribally-initiated research may differ from CBPR, particularly when tribal governments have their own funding for the projects, is that tribes have essentially complete control over the project reports (Model Tribal Research Code, 1999; Ortiz, 2003; Brugge & Missaghian, 2006; Nilson et al., 2008). While issues may still surface with contractors who inappropriately publish or use data, most tribal contracts in Arizona specifically state that data produced as part of a contract is owned by the tribal government and that any use of data has to be formally approved by tribal government (Arizona Biomedical Research Commission, 2006).

As part of good-government practice and because tribal budgets include federal and other funds, tribes have established procedures, contract language and oversight/audit capabilities to manage contractual research (Fisher & Ball, 2003; Manson et al., 2004; Canadian Institute of Health Research, 2007). These capacities, tools and procedures can also be very helpful in controlling research that does not use tribal funding or is initiated outside the tribal government in which the tribe decides to participate. Projects that use federal funding are subject to federal research requirements (like

Institutional Review Board review) and federal agencies and other institutions may require that research projects be led by Principal Investigators who have certain credentials (e.g., Ph.D.); in some cases federal or other funding agencies may require that research teams be university-based (World Health Organization, 2003; Arizona Biomedical Research Commission, 2006). The research projects that are initiated elsewhere, but in which tribes agree to participate, require more formal structure, regulation and procedures to produce the results of TDPR.

In the ideal TDPR model, all research would be based upon on-going, internal planning and discussions that lead to a governmental decision to conduct a research project. However, there may be situations in which tribal governments determine that research opportunities generated from non-tribal processes are potentially useful. Both internally-generated as well as 'opportunistic' TDPR may fit with the strategic goals of a tribe. One of the reasons tribal governments may seek out collaborators in conducting research is the high cost and infrastructure requirements for research, particularly biomedical research (Edwards et al., 2008). However, if it is possible for the tribe to be the proposal applicant, even if it seeks assistance in developing the proposal and chooses to subcontract parts of the work, it is still in a good position to control the research overall.

TDPR: Specific Principles, Methods and Tools

Full Participation and Social Validity

A core principle of CBPR is to have communities participate as early as possible in designing the research effort (Macaulay et al., 1998; Davis & Reid, 1999; Burhansstipanov et al., 2005). For TDPR, the ideal is the scenario in which a tribe has conducted a strategic planning process or identified a research need and decides to undertake a project (Israel et al., 2001; Letendre & Caine, 2004; Gibson et al., 2008). However, in cases in which agencies or institutions approach tribes to participate in research projects, TDPR principles would require that the tribe participate in the earliest possible planning stage and come to full agreement on the goals, design and implementation of the project (Macaulay et al., 1998; Davis & Reid, 1999; Hodge et al., 2000; Israel et al., 2001; Garwick & Auger, 2003; World Health Organization, 2003). Development of a project-specific agreement could include language that clarifies ownership of data, review of analysis and approval of publications (Model Tribal Research Code, 1999; Inuit Tapiriit Kanatami, 2003; Manson et al., 2004; Arizona Biomedical Research Commission, 2006).

Many studies on CBPR point out that community readiness is generally highest when research projects develop from internal community processes (Stoddart et al., 2000; Israel et al., 2001; Baydala et al., 2006). Without substantial social validity, in which participants understand the goals and process and believe that the results are valid, the project may fail to achieve its goals (Ortiz, 2003; Burhansstipanov et al., 2005; Christopher, 2005). Community-wide support and community readiness are key variables in successful implementation of research (Christopher et al., 2008). It can be a significant challenge to successfully conduct a research project if the initial buy-in that comes from participatory planning does not occur (Ortiz, 2003). It may be impossible to implement outcomes, recommendations or findings (Fisher & Ball, 2003).

Informed Consent for Tribally-Driven Research Projects

Informed consent by individuals is a difficult issue for the public as a whole; the more an individual knows about a field of study, the greater that individual's ability to appreciate the potential consequences, both positive and negative, of participation in a research project. In general, most research projects use a written form to obtain consent (World Health Organization, 2003; Arizona Biomedical Research Commission, 2006). The language in the form needs to be understandable

(potentially in English and the native language), to fit comfortably with the culture and be fully informative (Beauvais, 1999; Hodge et al., 2000). Written forms are useful for records and can serve as mnemonic devices when information needs to be verbally explained so that the researcher obtaining the consent covers all the information in a similar way each time. In cases in which the individual giving consent does not read or speak English, projects make use of interpreters or witnesses to confirm an individual's consent (Hodge et al., 2000; World Health Organization, 2003; Holkup et al., 2004). In some cases, projects have taped (including video-taped) explanations and consents and kept them as part of the project records (Brown, 2005; Nilson et al., 2008).

When a tribal government generates a research project, the budget and concept as well as the contract may be approved by a council resolution (Fisher & Ball, 2002; Fisher & Ball, 2003). In cases when a tribe is asked to participate in a research project generated from outside, it is also critical to obtain council approval (Arizona Biomedical Research Commission, 2006). Some tribes may require a contract, research agreement or resolution be presented and approved by a standing committee or an IRB in addition to the council (Fisher & Ball, 2003). In some cases, it may be acceptable to get the written approval of the highest elected tribal official, but it may be still be useful to obtain council approval (Hodge et al., 2000; World Health Organization, 2003). Inexperienced researchers, particularly in universities, often make the mistake of thinking approval from a director of a tribal department is tribal government approval (Burhansstipanov et al., 2005).

Gathering Data

Many CBPR practitioners note that survey methods are particularly vulnerable to producing invalid results in communities that are remote, speak languages other than those of the researchers, and when literacy among study population segments is limited (Hodge et al., 2000; Burhansstipanov et al., 2005). These issues are also critically important in TDPR. Language and vocabulary need to be fully vetted and culturally appropriate (Arizona Biomedical Research Commission, 2006). If translation is required and if literacy is a challenge, it is critical to have tribal team members to translate and explain the surveys and record responses accurately (Caldwell et al., 2005; Edwards et al., 2008). Other standard variables that affect survey validity in tribal communities include the lack of phones in many homes and the potential for low response rates (Hodge et al., 2000; Stoddart et al., 2000; Burhansstipanov et al., 2005). Because of these well-known issues, few TDPR projects rely solely on survey methods and may not use them at all. TDPR has a much stronger reliance on talking methods of gathering data, particularly interviews, focus groups and variants such as talking circles (Hodge et al., 1998; Burhansstipanov, 1999; Fisher & Ball, 2002; Garwick & Auger, 2003; Manson et al., 2004; Brugge & Missaghian, 2006; Nilson et al., 2008). Many health-related projects have made excellent use of patient 'navigators' or 'sisters/brothers' who are tribal members (Burhansstipanov, 1998). These project staff receive training and provide language translation, decode technical terms and are available to participants to answer questions in a non-public and low-key setting (Hodge et al., 2000; Stoddart et al., 2000; Caldwell et al., 2005; Edwards et al., 2008).

It is sometimes useful to have researchers, particularly on projects dealing with sensitive, personal data, who are not part of the local community; participants may feel uncomfortable sharing information with people they know (Beauvais, 1999; Caldwell et al., 2005; Buchwald et al., 2006). Sometimes it is easier to talk to a stranger about health-related behaviors than to a neighbor, provided the outsider is respectful and keeps the information completely confidential (Hodge et al., 2000).

Most of the literature on tribal research, like CBPR in small communities, notes that it can be a significant challenge to maintain confidentiality and to protect the identity of respondents and participants in small communities (Beauvais, 1999). Information can sometimes identify sources in

communities in which everyone knows everyone else. Particular care needs to be devoted to these issues in the research design and in training the research team on a TDPR project.

TDPR Builds on Existing Strengths and Builds Capacity and Produces Both Short and Long-term Benefits

Another core principle of TDPR is that it builds on existing tribal strengths and empowers tribal governments and communities (Arizona Biomedical Research Commission, 2006). Empowerment means that tribal governments and tribal members gain skills and confidence as they are active 'agents' who can investigate their own situations and implement their own solutions (Davis & Reid, 1999; Garwick & Auger, 2003; Ortiz, 2003; Holkup et al., 2004; Letendre & Caine, 2004; Baydala et al., 2006; Teufel-Shone et al., 2006; Christopher et al., 2008). In TDPR, planning and data gathering may include identification of 'what is working well' in order to build on strengths rather than just focusing on problems. Often these existing strengths will be the key networks (for example, youth, families, elders, organizations, health programs) that are critical for recruiting individual participants into a research project and for implementing any findings or recommendations for action (Hodge et al., 2000; Israel et al., 2001; Stubben, 2001; Garwick & Auger, 2003). There is a potential and useful multiplier-effect of building on and strengthening institutions, processes or organizations that are already working well within tribal communities (Burhansstipanov et al., 2005).

TDPR builds tribal capacity at every step within a research project in the form of providing training and jobs and bringing in additional funding, that can be used for buying equipment software or other items that the tribe can continue to use in the future (Israel et al., 2001; Manson et al., 2004; Arizona Biomedical Research Commission, 2006). For decades, the Inter Tribal Council of Arizona, Inc. has empowered tribal governments by coordinating working groups and providing research training in a wide range of areas, including the train-the-trainer Cancer 101 (Arizona Biomedical Research Commission, 2006). While outside researchers may provide the capacity-building resources, local community or tribal colleges may provide training to tribal interviewers who can thus also earn academic credit (Israel et al., 2001; Fisher & Ball, 2002; Burhansstipanov et al., 2005).

The ASU American Indian Policy Institute recruits students from the tribes that have contracted with the Institute to work with them on projects. The students get academic credit for the project and usually get paid to work on it as well. The students also get field experience to complement their classroom instruction and they learn about their own tribe. The tribe sees its member-students getting academic credit and financial benefit from the project and that a tribal member is bringing connections and insights to the project team; this is a true win-win-win capacity-building scenario. All five of the student interns who worked on research projects through the ASU American Indian Policy Institute finished their degrees and have been hired as high-ranking administrators in their tribes or have gone on to graduate school.

Tribal governments may also seek specific, short-term practical benefits as part of TDPR projects that may also have longer-term goals. In one TDPR project, the tribe required development of a Guidebook on Patient-Provider Communication as a project task so that the collaborative training of health providers and 'project navigators' could be written down and distributed more widely (Garwick & Auger, 2003; Baydala et al., 2006). In TDPR, tribal departments, leaders, tribal members and other tribal organizations are strengthened and, as a consequence, tribes expand their willingness and capacity to investigate and solve issues (Salsberg et al., 2007). Ultimately, tribes are further empowered by TDPR in which the information, analysis and outcomes are well understood, meaningful and provide increased ability to improve people's lives.

Tribes are Governments: Core Significance of TDPR

Tribal Research Codes and Tribal Research Review Boards/Institutional Review Boards; Tribal Research Agreements and Partnerships

The major tool used by tribal governments to control research that directly affects them is to enact tribal research codes (Model Tribal Research Code, 1999; Fisher & Ball, 2002; Fisher & Ball, 2003). Most non-tribal communities involved in CBPR do not have these governmental authorities (Stubben, 2001). The American Indian Law Center developed a model tribal research code in the late 1990s (available on their website) that includes establishment of a tribal research review board with specific duties and authorities, similar to Institutional Review Boards (IRB's) in federal agencies and universities. Much of the existing work on tribal research codes and tribal IRB's (or review boards) is focused on health research (Hodge et al., 2000; Manson et al., 2004). The Navajo Nation's research review board is called the Health Research Review Board, although the board now oversees other research areas (Brugge & Missaghian, 2006). Increasingly throughout the U.S., tribal review is considering a wide range of research, including ethnographic, cultural and environmental research projects (Model Tribal Research Code, 1999).

It is particularly valuable for tribal governments to enact tribal research codes because university IRB's are able to require that their researchers comply with tribal laws and regulations just as they require compliance with international, federal and state laws (Brown, 2005; Brugge & Missaghian, 2006). In the absence of a tribal code, university IRBs apply federal laws and university requirements which are generally limited to research design and protection of individuals (Model Tribal Research Code, 1999). Only a tribal code or specific agreement can require that a researcher obtain tribal approval before publishing an article or report (Beauvais, 1999; Inuit Tapiriit Kanatami, 2003; World Health Organization, 2003; Letendre & Caine, 2004; Arizona Biomedical Research Commission, 2006). Tribal research codes can require tribal review of proposals and spell out a process for that review, clearly establish expectations, require tribal approval of any publication or use of the data, confirm intellectual property rights, and address a range of other specific requirements (Model Tribal Research Code, 1999; Fisher & Ball, 2002; Arizona Biomedical Research Commission, 2006; Brugge & Missaghian, 2006). Importantly, a code can also specify the process for ensuring compliance and enforcement including denial of future access as well as issuance of administrative or judicial penalties and fines (Model Tribal Research Code, 1999). In general, most researchers appreciate having an established process and set of rules to follow; although a statutorily required review process may seem burdensome, it is clear and relatively stable.

As most tribal governments do not currently have research codes, tribes may consider developing specific project agreements with research organizations that lay out expectations and requirements similar to a code (Baydala et al., 2006; Christopher et al., 2008). The Salt River Pima Maricopa Indian Community developed an agreement with the Translation Genomics Research Institute (TGEN) for a project initiated by the tribe; the agreement has many elements of a tribal research code (Arizona Biomedical Research Commission, 2006). An overarching agreement could lay out the core elements of a long-term relationship and specific 'contracts' for individual projects could become addendums. Developing agreements allows for more flexibility in working with different organizations and promotes long-term partnerships, critical to CBPR and TDPR.

In order to make effective use of time and resources, tribal governments may decide to pool their resources and work with an inter-tribal review board (Baydala et al., 2006). The Inter Tribal Council of Arizona, Inc. is exploring this concept because of the overall number of research projects conducted by and with the numerous tribes within the state (World Health Organization, 2003). Maintaining the structure and expertise for an effective IRB may take more resources than many tribal governments can commit at this time.

Tribal Governments Ownership of Data and Participation in Interpretation and Analysis; Control of Data, Dissemination of Data and Results; Rights to Intellectual Property

Many researchers note that tribes and tribal communities are interested in obtaining high quality data and cutting edge analyses; they want good science and data to help with their decision-making and policy-setting. In general, tribal research concerns focus on the presentation of the analysis (Christopher, 2005). Often tribes insist on the opportunity to participate in the interpretation of the findings because of past experiences with research that produced information that was misleading or simply inaccurate (Davis & Reid, 1999; Garwick & Auger, 2003; Letendre & Caine, 2004; Brown, 2005; Burhansstipanov et al., 2005; Arizona Biomedical Research Commission, 2006; Christopher et al., 2008). This experience is very similar to researchers who may feel that they are misquoted by the media and feel slighted that they do not have a chance to review newspaper articles written by reporters before they are published. There do not appear to be examples of tribes intervening in data analysis based on political interest in censorship (Manson et al., 2004). A concern over censorship is often cited by academics who point out that political censorship is in conflict with principles of academic freedom (Macaulay, 1994; Fisher & Ball, 2003). Researchers also point out that when federal dollars are involved in projects, they may be violating regulations and grant requirements if all data is not incorporated into the analysis (Ortiz, 2003).

Some methodological challenges may occur with clinical trials or trials that involve providing information about the health benefits of certain behaviors, in which a control group does not get information. These controls are critical to most scientific research designs but are often problematic for the tribal public. Experience suggests that concerns about controls are better handled in a TDPR context because follow-up is more likely to occur. The national diabetes study is such an example; during the nationwide study, it was determined that the approach of individualized counseling on diet and exercise was so successful, trials were stopped and agencies began implementing the program (Salsberg et al., 2007). If the research determines that a particular educational approach is useful, tribes can readily contact members of the control group to provide the information as quickly as possible.

Federal rules require that costs and benefits to the individual participants in health studies are weighed (Beauvais, 1999; World Health Organization, 2003). Research that might produce very useful results may still not be ethical or allowed because it may present risks to the individual participant that are too high (Ortiz, 2003; World Health Organization, 2003). As a parallel, tribes can be collectively harmed, stigmatized and suffer unwarranted criticism if data and analyses are inappropriately characterized, particularly if they become available to the media (Model Tribal Research Code, 1999; Brugge & Missaghian, 2006). Cases often cited in the tribal research literature include the Barrow Alcohol study in which the media inappropriately characterized the study results as showing that alcoholism was common in the community; as a result, local communities were denied funding for key projects (Davis & Reid, 1999; Manson et al., 2004; Caldwell et al., 2005; Christopher et al., 2008). Another often cited case of tribal stigmatization is the media labeling of the hantavirus as the 'Navajo' Flu following release of research data (Burhansstipanov, 1999; Davis & Reid, 1999; Manson et al., 2004; Brugge & Missaghian, 2006; Christopher et al., 2008). In part, these challenges may flow from the lack of training many scientists have in communicating with the public and the media and their use of technical vocabulary that the media view as jargon that needs to be simplified.

Tribal leaders as elected officials generally are experienced public speakers and tribes often have outreach and public relations staff skilled in getting across a message through the media (World Health Organization, 2003). Tribal governments have substantial experience in identifying trigger issues that may result in media mischaracterizations or reinforcement of negative stereotypes

(Holkup et al., 2004). As principles of TDPR emphasize, tribes have the authority to verify that data are accurate and complete by getting key players to review research reports (Holkup et al., 2004). Tribes have the authority to ensure that appropriate caveats or limitations on the data are made clear in research reports (Holkup et al., 2004). In addition, tribes, often through their attorneys and department staff, recognize data that may be considered sacred or confidential for legal reasons (Holkup et al., 2004). To protect legal rights as well as their culture and religion, tribes have the authority to review research reports that affect them (Davis & Reid, 1999; Holkup et al., 2004). In order to protect tribal interests and clarify procedures, it is ideal to address these issues of data confidentiality and tribal review in tribal research codes and agreements (Inuit Tapiriit Kanatami, 2003; Holkup et al., 2004; Manson et al., 2004; Arizona Biomedical Research Commission, 2006). It is essential that issues of review and presentation are clearly laid out in research agreements before activities begin (World Health Organization, 2003; Letendre & Caine, 2004; Brugge & Missaghian, 2006; Canadian Institute of Health Research, 2007; Nilson et al., 2008).

While an individual tribal member can authorize the collection of data for his/her own purposes, to the extent that individual's data may have an impact on the tribe, the information is still subject to a tribal agreement (Brown, 2005; Arizona Biomedical Research Commission, 2006). A review of the literature notes that native individuals have reported feeling offended when researchers sought tribal approval to obtain information that the individual feels he/she has the authority to share or not share. However, establishing tribal government authority and the review and approval process in a research code or agreement will help avoid such conflicts.

Publishing Academic Articles

For university faculty who are research partners in TDPR, the issues of publication can be difficult. The core criteria of tenure decisions remains authorship including sole-authorship articles published in peer reviewed journals (Strickland, 2006). As a result of its career implications, many non-tenured faculty members may be unwilling to participate in TDPR unless there is some potential for publication. When articles are written as part of TDPR, they generally recognize the contributions of all the research team; most TDPR reports and articles list the tribal members of the research team as co-authors (Macaulay et al., 1998; World Health Organization, 2003; Arizona Biomedical Research Commission, 2006; Christopher et al., 2008).

Encouraging universities to give recognition for tribally solicited research reports and for publications with multiple authors may be an area in which tribal governments can provide support to their long-term academic partners. Tribal governments have the authority to require review of articles before publication; once again, establishing this authority and the review and approval process in a research code or agreement will avoid conflicts after the research project is underway or concluded. Tribes may choose to establish a dispute resolution procedure for disputes over publication, but ultimately tribal governments have the authority to make the decision whether and how information is published and made available to the public and media (Macaulay et al., 1998; Ortiz, 2003; Brugge & Missaghian, 2006).

In practice, there do not appear to be many cases in which a tribe has denied permission for publication to a researcher, particularly if a review and approval process has been established before research begins. The literature cites very few examples, although it may be inherently difficult to find published information on these cases (Brugge & Missaghian, 2006). It is more common to hear of researchers moving on to other projects because of the timeframe for obtaining tribal council or IRB approval to conduct research (Fisher & Ball, 2003; Manson et al., 2004; Brugge & Missaghian, 2006). This challenge seems particularly relevant to undergraduate or graduate students seeking to conduct short-term projects within their own tribal communities. There are cases of students seeking to write

papers for courses, who become frustrated with the bureaucracy of tribal review boards because the semester ended before they received IRB approval for their research project. There are also cases of tribal employees, both native and non-native, seeking tribal government permission to use their work settings (and in some cases work-related data) for graduate theses and dissertations, who are denied permission. It may be useful to develop a better understanding of the situations in which tribal permission to conduct research has been denied. The evidence suggests, not surprisingly, that approval for publication is significantly enhanced when the research project is initiated by the tribal government itself and the procedures for tribal review are clearly established up front (Brugge & Missaghian, 2006).

What Are the Next Steps?

What are the structural supports that still need to be developed to support TDPR? What are the structural and institutional barriers? While the core principles of CBPR have been implemented for several decades and many elements of TDPR are being implemented by tribes throughout the United States and Canada, TDPR is still in its formative stage. Some elements have been institutionalized by governmental and non-governmental funding agencies and universities are starting to develop policies and establish research units incorporating the principles of TDPR (Davis & Reid, 1999; World Health Organization, 2003; Letendre & Caine, 2004; Brown, 2005; Arizona Biomedical Research Commission, 2006; Baydala et al., 2006; Strickland, 2006; Canadian Institute of Health Research, 2007; Edwards et al., 2008). But what is the level of understanding and overall penetration of the core principles within universities, non-governmental funding sources, governmental agencies and even tribal governments? How many researchers or bureaucrats understand or have even been exposed to the basic concepts of tribal sovereignty, self-determination and Tribally-Driven Participatory Research?

There is considerable work to be done by tribal governments, tribal organizations, federal agencies, non-governmental organizations and universities, both internally and together. Many of the articles in the annotated bibliography included in this volume suggest steps to be taken to fully realize TDPR. The following section draws from these suggestions as well as lessons learned and promising practices derived from the Southwest American Indian Collaborative Network project.

Promising Practices

While the basic principles of TDPR may apply in general to tribal governments, tribes throughout the United States vary significantly in cultural traditions, governmental structure, size and a wide range of other variables (Davis & Reid, 1999; Hodge et al., 2000; Fisher & Ball, 2003; Letendre & Caine, 2004; Brown, 2005; Caldwell et al., 2005; Christopher, 2005; Brugge & Missaghian, 2006; Christopher et al., 2008). Rather than making an assumption of homogeneity by discussing 'best practices' that may apply across the board to tribes, it is often useful to think about 'promising practices' that tribes may want to consider and potentially modify for their own, unique situation.

It is the recognition that tribal governments are able to tailor their approach to TDPR that makes development of tribal research codes so promising. Rather than a national standard, or university policies, tribal governments have the authority to enact research codes that fit their specific situations and can evolve over time, based on needs.

Some useful tools have been developed and are available to tribal governments in implementing the principles of TDPR. Most of these came from federally-funded projects, such as the Southwest American Indian Collaborative Network (SAICN) that bring together tribes, universities, as well as state and federal agencies, using the support of inter-tribal organizations like the Inter Tribal Council of Arizona (Arizona Biomedical Research Commission, 2006). To advance TDPR, existing tools need to be made available on-line and presented in more workshops and conferences both regionally

and nationally. In addition, use of these tools and concepts needs to be expanded through funding for technical assistance activities such as those done by SAICN. Tribes and tribal organizations may want to encourage other agencies, such as the Administration for Native Americans and the National Science Foundation, to set aside funding for development of tribal research efforts.

Some of the existing tools include:

- Model Research Agreements (First Nations of Canada; WHO; Indigenous Peoples Council of Biocolonialism)
- Model Tribal Research Code (American Indian Law Center)
- Indigenous Research Protection Act Model (Indigenous Peoples Council of Biocolonialism)
- Enhancing Partnerships with the Native American Community (Handbook developed by the Arizona Biomedical Research Commission)
- Southwest American Indian Collaborative Network website (Inter Tribal Council of Arizona, Inc. which can serve as a clearinghouse)
- Tribal Research Review Boards and Institutional Review Boards (IRB's).

A number of tribes have developed research review boards and the Navajo Nation has met the Indian Health Service requirements to take on the regulatory role of IRB for federally-funded biomedical research projects (Manson et al., 2004; Brugge & Missaghian, 2006). Unless a tribe has a fairly regular flow of research proposals to review, it may be difficult for tribal policy-makers to allocate the on-going funding required to develop and maintain the capacity for a research review board. There may be a role for inter-tribal organizations that can maintain staff to provide technical and logistical support to tribal governments for research proposal review; this approach would also provide more opportunity for tribes to gain experience and develop increased capacity in this area before determining the optimum strategy for managing research goals and projects.

Tribes and universities may benefit by collaboratively determining if there is a role for university IRB's in situations in which tribes select academic units or university faculty to work on tribal research contracts, particularly those that are tribally funded. Tribes, possibly in collaboration with universities, may want to develop expedited or generalized procedures for research projects conducted by undergraduate students, particularly by tribal members, especially when students need to complete their work within the timeframe of one academic semester.

Universities with Native faculty or faculty with extensive experience working successfully with tribal governments would benefit by making maximum use of these faculty resources in reviewing tribal research projects. Tribal governments may find it useful to include faculty as ex officio advisors on their IRB's. The Indian Health Service Aberdeen Area has appointed tribal representatives to its IRB, and universities may want to find a role for tribal government representatives in their IRB process for tribal research projects, even if only in an advisory capacity (Letendre & Caine, 2004; Manson et al., 2004; Brown, 2005).

Building Partnerships Based on Trust: University Policies, Training and Self-Certification

Policies and Procedures

Universities with a strong interest in building long-term partnerships with tribes will significantly enhance that effort by developing policies and procedures that affirm the principles of TDPR and build trust with tribal governments and communities (Davis & Reid, 1999; Israel et al., 2001; Brown, 2005; Strickland, 2006). It would particularly facilitate and expedite TDPR for tribes and universities to develop standard contract or agreement language concerning resolution of disputes, non-

disclosure of data and issues of review and approval of publications. Academic institutions are able to negotiate terms with industry and deal with proprietary data that preserve the scientific integrity of researchers and institutions while making use of the private research dollars to fund faculty and staff, train graduate students and expand research capacity through the purchase of equipment and construction of facilities.

In Arizona, Governor Janet Napolitano directed each state agency, including the University Board of Regents, to develop a tribal consultation policy. As a result, the Arizona Board of Regents (ABOR) recently enacted a Tribal Consultation Policy that incorporates goals for consulting with tribes on research issues and projects that affect them; the ABOR tribal policy then directs the three state universities to develop their own policies and procedures to implement the ABOR policy.

As with all policies and procedures, there is a significant need for training faculty and administrators within academia as well as in federal and state agencies about the ABOR policy. In addition, it is necessary to provide on-going training to maintain awareness and to reach new employees.

Training and Self-Certification

To continue the development of TDPR, tribes, tribal organizations, universities and research funding agencies may want to develop training programs that orient researchers to the concepts of TDPR. In order to avoid conflicts and to continue to build relationships, universities may want to require that all faculty, research staff and graduate assistants obtain appropriate training before working on research projects with tribal governments (Strickland, 2006). Core elements of training programs could be made available on-line, similar to requirements by certain federal agencies that grantees and researchers demonstrate a basic awareness of agency rules by taking an on-line test.

In addition, to avoid potential conflicts concerning academic freedom, TDPR may be advanced by the development of a national self-certification program in which researchers voluntarily commit to the principles of TDPR. Such a self-certification program could also be placed on-line, and a registry of researchers could be maintained who completed the training and commit through self-certification to follow the principles of TDPR in their work. The National Congress of American Indians Policy Research Center could fill this role and make the registry readily available to interested tribal governments. Importantly, tribes will want to determine that sub-contractors and all research and graduate assistants on specific projects have received training and have self-certified in situations in which the self-certification is a deciding factor in entering into collaborative research projects.

Trans-disciplinary Approaches for Complex Research Issues

Historically, one of the reasons that research with tribes may not have fulfilled expectations is the uni-dimensional approach and narrow focus of many funding agencies and in some cases the focused interests of individual researchers (Christopher, 2005; Brugge & Missaghian, 2006; Edwards et al., 2008). Often, goals tribes seek to obtain through research are complex and require understanding and involvement of many tribal institutions at many levels, including individuals, families, networks, organizations and governments. In order to achieve results, trans-disciplinary research needs to become the gold standard in TDPR, going beyond multi-disciplinary approaches by fully integrating the perspectives of a wide range of expertise, knowledge and perspectives (Arizona Biomedical Research Commission, 2006; Salsberg et al., 2007). Trans-disciplinary research units, such as the Arizona State University American Indian Policy Institute, are able to pull together teams of researchers with diverse expertise from throughout the university. In addition, research units with extensive experience working with tribes are in a good position to orient the academic research team members to TDPR.

Publishing

One of the core principles of collaborative TDPR is to determine expectations up front and resolve any issues through a contract or research agreement; in TDPR, in which universities are partners, the issues associated with review and permission to publish articles are an essential element of contract and agreement negotiations. Untenured faculty and graduate students tend to be very reluctant to participate in TDPR because they are under relentless pressure to publish (Fisher & Ball, 2003; Brugge & Missaghian, 2006). Tenured faculty may be willing to participate in TBPR projects if they have an interest, but they are less 'hungry' to join large-scale research projects than younger, non-tenured faculty and they still may face the same need to publish to obtain promotions. Academic institutions, tribes, inter-tribal organizations and research funding agencies may be able to mitigate some of the concerns of university-based research by working to establish journals that focus on TDPR and understand the value of articles with multiple-authors who participated on research teams (Israel et al., 2001). Such journals would simultaneously make TDPR more visible, increase awareness of the results that come from TDPR and provide more publishing outlets for university faculty and students. There may also be an opportunity for a coalition to advocate with established journals to publish more articles on TDPR.

Collaborative Efforts and Results

Given that TDPR, like CBPR, takes more coordination, time and funding, it is critical to document results, such as improvements in health, and make those results available to funding agencies to justify and encourage additional support. The Southwest American Indian Collaborative Network is an outstanding multi-year effort that focuses on results that are important to the tribal participants. SAICN accomplishes this goal by providing technical assistance to tribes in building health research capacity and developing long-term collaborations among tribes, agencies and universities.

CONCLUSION

Tribal governments are in a strong position to conduct and manage the research they need to achieve their goals. Consistent with the core principles of Tribally-Driven Participatory Research, tribal governments are building their internal capacity to conduct research through their own projects as well as in partnerships with universities and other organizations. As governments, tribal nations are able to set specific research standards and protocols through tribal statutes as well as through formal agreements that clearly lay out tribal authorities.

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