Nursing *Inquiry*

Nursing Inquiry 2010; **17**(4): 359–372

Feature

The Family Education Diabetes Series (FEDS): community-based participatory research with a midwestern American Indian community

Tai J Mendenhall,[a] Jerica M Berge,[a] Peter Harper,[a] Betty GreenCrow,[b] Nan LittleWalker,[b] Sheila WhiteEagle[b] and Steve BrownOwl[b]

[a]*University of Minnesota Medical School, Minneapolis, MN, USA,* [b]*St Paul Area Council of Churches*

Accepted for publication 2 August 2010

MENDENHALL TJ, BERGE JM, HARPER P, GREENCROW B, LITTLEWALKER N, WHITEEAGLE S and BROWNOWL S. *Nursing Inquiry* 2010; **17**: 359–372

The Family Education Diabetes Series (FEDS): community-based participatory research with a midwestern American Indian community

Indigenous people around the globe tend to struggle with poorer health and well-being than their non-indigenous counterparts. One area that this is especially evident is in the epidemic of diabetes in North America's American Indians (AIs) – who evidence higher prevalence rates and concomitant disease-related complications than any other racial/ethnic group. As researchers and AI communities work together to transcend conventional top-down, service-delivery approaches to care, community-based participatory research is beginning to show promise as a way to partner contemporary biomedical knowledge with the lived-experience, wisdom, and customs of Indigenous people. This study describes the Family Education Diabetes Series (FEDS) as an example of such effort, and highlights pilot findings assessing its value and impact across key diabetes-relevant variables. Following 36 intervention participants across baseline, 3-month, and 6-month time periods, data show significant improvements in weight, blood pressure, and metabolic control (A1c). Strengths and limitations of this investigation are presented, along with suggestions about how to further advance and empirically test the work across other Indigenous communities.

Key words: action research, American Indians, community-based participatory research, diabetes, indigenous people, obesity.

Indigenous people around the globe tend to struggle with poorer physical health and well-being than their non-indigenous counterparts. One area that this is especially evident is in the epidemic of diabetes in North America's American Indians (AIs) – who evidence higher prevalence rates and concomitant disease-related complications than any other racial/ethnic group. As researchers and AI communities work together to transcend conventional top-down, service-delivery approaches to care, community-based participatory research (CBPR) is beginning to show promise as a way to partner contemporary biomedical knowledge with the lived-experience, wisdom, and customs of Indigenous people. The Family Education Diabetes Series (FEDS) was designed and implemented through a CBPR approach involving local elders and leaders in a Midwestern United States AI community and healthcare providers and researchers affiliated with the University of Minnesota (UMN) Medical School. The main aim of this study is to describe and report pilot data from this innovative project.

Correspondence: Tai J. Mendenhall, Department of Family Medicine and Community Health, University of Minnesota Medical School, 717 Delaware St SE; Suite 422; Minneapolis, MN 55414, USA.
E-mail: <mend0009@umn.edu>

DISPARITIES IN INDIGENOUS HEALTH

The world's Indigenous people span every inhabited continent on the globe and encompass thousands of cultures, ethnicities, religions, languages, and mores. And although the rich diversities within these groups are integral to their unique and respective identities, all share in the profound adversities they have endured through the colonization of their people and lands by powerful outsiders who later dominated them and eradicated (or attempted to eradicate) their ways of life (Gracey and King 2009). Of the estimated 370–400 million Indigenous people in the world today, almost all are over-represented among the disadvantaged and poor, and their overall health and well-being is comparatively worse than their non-indigenous counterparts. From high infant mortality to shortened total life expectancy, to diseases and deaths caused by cigarette smoking, alcohol and drug abuse, unhealthy lifestyles (e.g. obesity, hypertension, diabetes), and environmental contaminations – Indigenous people are the hardest hit (Gracey and King 2009; King, Smith, and Gracey 2009).

Indigenous health in North America

North America's (including Canada and the United States) Indigenous people, known collectively as 'Native Americans', include more than 560 recognized tribes and groups (e.g. Canada's First Nation, Metis, and Cree; US Lakota, Sioux, Ojibwe) (King, Smith, and Gracey 2009). Their health status is consistent with Indigenous groups' health trends across the world, insofar as they fare worse in nearly every physical and mental health category that is documented compared to their non-indigenous counterparts (Chateau-Degat et al. 2009; Kahn and Khan 2009; King, Smith, and Gracey 2009; Oster and Toth 2009; Roberts et al. 2009). Principal reasons attributed to this are myriad, including (but not limited to) poverty, malnutrition, poor hygiene, overcrowding, and poor access to preventive health services (Roberts et al. 2009). Increased urbanization is especially noteworthy as it relates to lifestyle problems (e.g. obesity, diabetes), and as engagement in physical activity declines and consumption of highly processed and fatty foods increases. Hereditary factors associated with populations of hunter-gatherers are also viewed as contributing to these disparities vis-à-vis contemporary trends in urbanization; explanations have been proposed about how Native Americans survived sporadic food availability under feast-or-famine conditions through rapid and elevated insulin secretion and excessive caloric intake. These hypotheses are continually evolving as our understanding of metabolism and diabetes mellitus evolves (Bindon and Baker 1997; National Diabetes Information Clearing House (2002); King 2004).

American Indians and diabetes

Across both the United States and Canada, diabetes is recognized as one of the most widespread lifestyle-related diseases affecting Native Americans – and it is to this issue that the present investigation was focused. Aligning closely with epidemiological data in its sister North American country of Canada, current prevalence estimates for diabetes in the USA exceed 7% of the general population (Centers for Disease Control and Prevention 2009; National Heart Lung and Blood Institute 2004; National Institute of Diabetes and Digestive and Kidney Diseases 2007). Disparities in health status related to diabetes and its myriad complications and eventual sequelae are well documented; the AI population – referring to the estimated 2.5 million Native Americans residing in the USA – is especially affected, with prevalence rates as high as 50% among some tribes (Rhoades and Buchwald 2003; Indian Health Service 2005; United States Census Bureau 2010) alongside higher rates of disease-related complications such as co-morbid heart disease, reduced or lost vision, amputations, kidney disease, and depression compared to Caucasian and all other racial/ethnic groups (Indian Health Service 2005; National Institute of Diabetes and Digestive and Kidney Diseases 2007; Sahmoun, Markland, and Helgerson 2007; Jiang et al. 2008, 427).

Diabetes interventions for American Indians

The healthcare industry has struggled to successfully reach the AI community though traditional care delivery systems (WhiteEagle 2005). In prior studies of type 2 diabetes control in the AI population, interventions did include a component of basic education regarding AI culture (e.g. traditional foods; e.g. Ponchilla 1993; LeMaster and Connell 1994; Carter et al. 1997; Hood et al. 1997; Gilliland et al. 2002; Keltner, Kelley, and Smith 2004); however, these initiatives primarily targeted lifestyle changes and medical management of the disease – that is, traditional healthcare delivery – rather than working to increase 'ownership' of the problem by individual patients, families, and communities. Advancing diabetes management within the AI community is an under-researched area.

Another notable gap is that most research has been conducted with AIs living on reservations. This is due, at least in part, to the presence of the Indian Health Service (IHS) and researchers' want for recruiting large homogeneous samples. Urban-dwelling AIs have been largely overlooked in diabetes studies; this is problematic because it is increasingly common for AIs to live in metropolitan settings, and (as outlined above) because urban-dwelling AIs generally have poorer health and greater health disparities than those living on reservations (Urban Indian Health Institute 2004; WhiteEagle 2005). Up to 70% of AIs now reside outside of reservations; the few studies that have been conducted on their health indicate that large segments of this group experience considerable difficulties in obtaining primary and preventive health-care as a consequence of their socioeconomic condition and the absence of IHS in many urban areas (Taylor 1988; Kramer 1992; Rhoades and Buchwald 2003; Urban Indian Health Institute 2004). Only recently have efforts in community engagement and provider–patient partnerships in the AI community been attempted with the urban AI community; these are relatively new and require more development (Mendenhall 2002; Doherty and Mendenhall 2006).

Many providers and communities of patients are now looking to (and engaging in) novel and collaborative partnerships that honor and tap resources across professional and patient groups alike – and to position these efforts in the very communities that diabetes is of most concern. CBPR, described in more detail below, represents a leading methodology herein as it emphasizes close collaboration between professional researchers and lay community members (Lewin 1946; Minkler and Wallerstein 2003; Mendenhall and Doherty 2005). Hierarchal differences are flattened through this partnership as all participants work together to generate knowledge and solve local problems. Principal reasons justifying this approach rest in its contrast to AI people's experience with conventional research (i.e. conducted by outsiders through top-down, expert-driven methods) that has tended to benefit researchers more than AIs (e.g. professional prestige, tenure), pathologized AIs as dysfunctional, and not directly informed or advanced the communities they were supposed to help (e.g. study results not shared with AIs) (Davis and Reid 1999; Burhansstipanov, Christopher and Schumacher 2005; Gone 2006). Emerging CBPR projects in AI communities, while still focusing on children more than adults, support the utility of CBPR efforts in co-creating medically sound programs that are sensitive to local customs and cultural traditions (Steckler et al. 2002; Garwick and Auger 2003; Potvin et al. 2003; Castro et al. 2009). The FEDS was designed and implemented through a CBPR approach involving local elders and leaders in the AI community through the St Paul Area Council of Churches' Department of Indian Work (DIW) and healthcare providers and researchers affiliated with the UMN Medical School. Targeting urban-dwelling AIs in the Twin Cities of Minneapolis/St Paul, the FEDS represents a purposeful integration of western medicine and AI cultures. The main aim of this study is to describe and report pilot data from the FEDS project.

COMMUNITY-BASED PARTICIPATORY RESEARCH

Since its early coining of 'action research' by Kurt Lewin in the 1940s, many have contributed to advancing an investigative orientation wherein academic and professional researchers partner and collaborate with communities who are directly affected by an issue to generate knowledge and solve local problems (Lewin 1946, 34; Agency for Healthcare Research and Quality 2004; Mendenhall and Doherty 2005; Berge, Mendenhall, and Doherty 2009). Approaches within this larger frame vary in and across the degrees to which professionals and community members are involved in facilitating group processes, engaged in decision-making and change sequences, and roles/experiences as (co)learners (Cornwall and Jewkes 1995; Bell et al. 2004; Wallerstein and Duran 2006), and have been recognized by unique and overlapping terminologies and labels like 'participative research' and/or 'participatory research' (PR), 'participatory action research' (PAR), 'development leadership teams in action' (DELTA), 'critical action research', 'collaborative inquiry', 'co-operative research', 'appreciative inquiry' and others that purposively exclude the word 'research' so as to emphasize learning and change processes per se (e.g. 'participatory action learning', 'participatory action development') (Rahman and Fals-Borda 1991, 24; Kemmis and McTaggart 2000, 567; Heron and Reason 2001, 179; Kelly, Mock, and Tandon 2001, 348; Ludema, Cooperrider, and Barrett 2001, 189; Pyrch and Castillo 2001, 379; Bell et al. 2004, 10; Torre and Fine 2005, 221; Baum, MacDougall, and Smith 2006, 854; Byrne and Sahay 2006, 71; Braithwaite et al. 2007, 61; Pyrch 2007, 199; Wilson, Ho, and Walsh 2007, 85; Cammarota and Fine 2008, 1; Classen et al. 2008, 2402). As large national and international organizations focused on health (e.g. Agency for Healthcare Research and Quality; National Institutes for Health, World Health Organization) have systematically called for – and advanced funding to support – community-driven and collaborative efforts to address complex health and social problems ill-suited for conventional top-down service delivery and research endeavors, 'community-based participatory research' (CBPR) has been put forth alongside 'action research' as an inclusive and characterizing 'umbrella' to connect these like-minded efforts (Agency for Healthcare Research and Quality 2004; Pan American Health Organization 2004; Edwards et al. 2008, 188; Bogart and Uyeda 2009).

Several key assumptions permeate CBPR projects, including: (i) recognition of the community as the principal unit of identity; (ii) democratic and equitable partnership between all project members (e.g. participants, community stakeholders, researchers) as collaborators through every stage of knowledge and intervention development; (ii) building on the strengths and resources within the community; (iv) promoting co-learning and capacity-building between and among partners; (v) deep investment in change that carries with it an element of challenging the status quo and improving the lives of members in a community or practice; (vi) cyclical process in which problems are identified, solutions to address problems are developed within the context(s) of the community's existing resources, interventions are implemented, outcomes are evaluated according to what is essential in the eyes of participants, and interventions are modified in accord with new information as necessary; (vii) project members' humility and flexibility to accommodate changes as necessary across any part of a project; (viii) disseminating findings and new knowledge to and by all partners and constituents in the investigative process; (ix) recognition that CBPR can be a slow and messy process, especially during initial phases of development; and (x) long-term engagement and commitment to the work (Bradbury and Reason 2003; Mendenhall and Doherty 2005; Strickland 2006; Scharff and Mathews 2008; LaVeauz and Christopher 2009; Doherty, Mendenhall, and Berge in press).

Community-based participatory research has gained credibility in medicine, nursing, public health, and behavioral health since the early 1990s because of its ability to inform understanding of patients' experiences, improve or generate services, facilitate community outreach and engagement, enhance education, and augment cultural awareness (Mendenhall and Doherty 2007; Tobin 2000; Ward and Trigler 2001; Chavez et al. 2003). Projects carried out through this method have effected improvements in asthma, dental and mouth-care practices, management of preoperative fasting, patient problem-solving skills, overall physical well-being, patient and practitioner satisfaction, patient–practitioner communication, and a number of other significant healthcare foci (Lindsey and McGuinness 1998; Hampshire et al.1999; Meyer 2000; Schulz et al. 2003; Mendenhall and Doherty 2005; Brugge et al. 2010; Lewis et al. 2010; Doherty, Mendenhall, and Berge in press).

The Citizen Health Care Model was designed purposefully as a CBPR method for medical and mental health professionals who work with families in community settings (Doherty and Mendenhall 2006; Berge, Mendenhall, and Doherty 2009; Doherty, Mendenhall, and Berge in press). Citizen Health Care begins with the notion that all personal health problems can also be seen as public problems. For example, ethnic disparities in diabetes can be viewed in terms of their implications for a minority community's sense of dignity and social pride. It views providers as citizens with knowledge and skills who work actively with other citizens (patients, families) who possess important knowledge and skills. This approach emphasizes close collaboration among researchers and community participants in knowledge-generation and problem-solving. Tables 1 and 2 outline the main principles and action strategies of this model. See Doherty and Mendenhall (2006) and Doherty, Mendenhall, and Berge (in press) for a complete review.

Table 1 Citizen Health Care Model core principles

The greatest untapped resource for improving health-care is the knowledge, wisdom, and energy of individuals, families, and communities who face challenging health issues in their everyday lives
People must be engaged as co-producers of health-care for themselves and their communities, not just as patients or consumers of services
Professionals can play a catalytic role in fostering citizen initiatives when they develop their public skills as citizen professionals in groups with flattened hierarchies
If you begin with an established program, you will not end up with an initiative that is 'owned and operated' by citizens. But a citizen initiative might create or adopt a program as one of its activities
Local communities must retrieve their own historical, cultural, and religious traditions of health and healing, and bring these into dialog with contemporary medical systems.
Citizen health initiatives should have a bold vision (a BHAG – a big, hairy, audacious goal) while working pragmatically on focused, specific projects

METHOD

The FEDS was designed and implemented through a CBPR approach involving local elders and leaders in a midwestern United States AI community and healthcare providers and researchers affiliated with the UMN Medical School. The following is a description of the initiative's evolution, which follows the general sequence of steps and CBPR action strategies informed by the Citizen Health Care Model (outlined in table 2) and early pilot data.

Table 2 Action strategies for citizen health-care

Action strategy	Rationale
Get buy-in from key professional leaders and administrators	These are the gatekeepers who must support the initiation of a project based on its potential to meet one of the goals of the healthcare setting. However, it is best to request little or no budget, beyond a small amount of staff time, in order to allow the project enough incubation time before being expected to justify its outcomes
Identify a health issue that is of great concern to both professionals and members of a specific community (e.g. clinic, neighborhood, cultural group in a geographical location)	The issue must be one that a community of citizens actually cares about – not just something we think they should care about. Additionally, professionals must care about the issue and have enough passion for it to sustain their efforts over time. It must be a 'pressure point'
Identify potential community leaders who have personal experience with the health issue and who have relationships with the professional team	Leaders should be ordinary members of the community who in some way have mastered the selected health issue in their own lives and have a desire to give back to their community. 'Positional' leaders who head community agencies are generally not the best group to engage at this stage – they bring institutional priorities and constraints
Invite a small group of community leaders (three or four people) to meet several times with the professional team to explore the issue and see if there is a consensus to proceed with a larger community project	These preliminary discussions help determine whether a Citizen Health Care project is feasible and begin creating a professional/citizen leadership group
Strategize how to invite a larger group of community leaders (10–15) to begin the process of generating the project	You must have a larger group invested in the process to facilitate a larger 'We' focus
Over the next 6 months have biweekly meetings using community organizing principles	The following key steps are crucial, but can be slow and messy: (i) explore the community and citizen dimensions of the issue; (ii) create a name and mission statement for the initiative; (iii) conduct one-on-one interviews with a range of stakeholders; (iv) generate potential action initiatives and process them in regards to the Citizen Health Care Model and existing community resources; (v) decide on a specific action initiative and implement it
Employ Citizen Health Care processes through out the project	The following steps will keep the initiative focused, strong, and increase sustainability: (i) democratic planning and decision-making at every step; (ii) mutual teaching and learning among community members; (iii) creating ways to fold new learnings back into the community; (iv) identifying and developing leaders; (v) using professional expertise selectively – 'on tap', not 'on top'; (vi) forging a sense of larger purpose

Establishing buy-in from key professional leaders and administrators

American Indian community leaders and tribal elders in the cities of Minneapolis and St Paul, Minnesota were worried about the ever-increasing prevalence of diabetes and its impact on their people. Through their administrative positions of power in the local St Paul Area Council of Churches' DIW and its collaborative relationships with a wide variety of community initiatives and healthcare sites oriented to serving their community, these leaders/elders grew even more alarmed by the acquiescent sense of defeat that they were hearing from those affected. Many AIs communicated to them (and to each other) that diabetes is to be expected – that it cannot be prevented because it is a 'curse' unto AI people. Professional leaders and administrators in the medical community – positioned across a range of healthcare sites serving a variety of clientele – were also becoming increasingly worried about their AI patients. What they were seeing echoed what they were reading about in professional and epidemiological literature: (i) AIs – as a group – were the hardest hit with obesity and diabetes compared to all other racial/ethnic groups; (ii) large segments – almost 50% – of the state's estimated 54,000 AI residents were residing in urban areas outside of the scope of readily accessible healthcare through IHS (American Indian Policy Center 2010; United States Census Bureau 2010); and (iii) nobody was feeling effective in their education and/or intervention efforts designed to improve AIs' health. In early 2001, as leaders/elders and administrators/providers across both community and medical sites discussed their respective and overlapping concerns, they agreed to begin working together to create something that neither could create by themselves.

Identifying the health issues: diabetes and obesity

Although diabetes per se seemed like an obvious and unanimously agreed upon health issue to focus on at the outset, a great deal of discussion (spanning several meetings) between the aforementioned administrators/providers and community elders/leaders took place before proceeding to the project's next developmental steps. The question 'Is this a problem?' was posed and considered, evaluating whether diabetes as a disease was something that the AI community shared in perceiving as problem alongside key AI and healthcare leaders. As these conversations proceeded, 'diabetes' was framed as including 'pre-diabetes' (defined here as people at risk for developing the disease by nature of their current health status) and within this frame, especially, those struggling with obesity. AI children in single-digit ages (e.g. 4 or 5 years old) weighing as much as 100 pounds, and adults and children alike maintaining BMI indexes >40 were discussed as commonplace, and the health issues (plural) of this group's early conversations evolved to include both diabetes and obesity as of elemental focus.

Identifying community leaders

As the group continued its work together, it identified potential leaders in the AI community who – despite so many of the odds recognized to be against them as AI people – had triumphed in controlling their weight and/or diabetes. These select few were identified through personal relationships with administrative leaders/elders and/or by nature of their public visibility as already-established and recognized persons looked up to within their local community (e.g. through the DIW itself, though local AI organizations) or healthcare/professional team. Through personal and group conversations about burgeoning ideas to 'do something' in the AI community regarding diabetes and obesity, these new leaders' want to participate and 'give back' to the AI people was affirmed and established.

Meetings with community leaders

Early meetings between select providers/professionals (two nurses, a physician, a mental health professional) and AI community leaders (two women and one man – all recognized as local elders who had effectively worked to improve their own health) ensued, during which time the issues of diabetes and obesity in the AI community were discussed in-depth. The group shared in its frustration with the failures of conventional care (e.g. primary-care clinics), educational programs (e.g. clinic- or school-sponsored diabetes education/classes), and community-outreach (e.g. pow-wows in which diabetes awareness-raising efforts were a part). As these providers and AI community leaders (authors of this study) continued to discuss past efforts and potential new directions in their respective and overlapping efforts oriented to diabetes, they decided to approach this challenge with a CBPR approach, using the Citizen Health Care Model as a guide.

Meetings with professional/citizen leadership group

Our original (small) group of engaged providers and community leaders then worked together to invite others into its conversations regarding diabetes and obesity in the AI community. In a similar manner to the way(s) that early community leaders were identified, members in this professional/citizen leadership group were recruited on the basis of their having personal experiences and stakes in the AI community around issues of diabetes/obesity.

Over the course of this early and ongoing work, considerable effort was spent in designing a partnership that was different than conventional top-down models of care. Community members worked to sensitize providers and clinical researchers to the process(es), pace, and importance of building trust within AI circles. As the team engaged in a series of meetings (twice a month for 6 months), group discussions, and AI community events, this trust evolved. Providers and researchers learned about AI culture, the diversity of cultures/tribes within this larger frame (e.g. Dakota, Ojibwe, Hocak), belief systems, and manners – all because they were allowed into the AI community itself. In turn, community members gained more insights into and regarding how western medicine is oriented, and thereby secured better understanding(s) into providers' habitudes and perspectives in care delivery.

This process took approximately 2 years to evolve and transpire, which is consistent with established literature regarding the development of authentic, trusting, and effective CBPR partnerships between professional providers/researchers and Indigenous people (Minkler et al. 2003; Burhansstipanov, Christopher, and Schumacher 2005). Our group (which eventually re-named itself the 'citizen action group') then worked collaboratively to develop the FEDS, organize recruitment strategies, consider and identify outcome measures, implement the intervention, collect data, and disseminate findings across professional and lay audiences and outlets.

Program description

The FEDS was first launched in 2003. Within the program, patients, their families (spouses, parents, children), and providers (physicians, nurses, dieticians, mental health personnel) are brought together and assembled every other week for an evening of fellowship, education, and support for 6 months. Generally six to seven providers, four to five tribal elders, and 35–40 community members attend. Meetings begin with members checking and recording each other's blood sugars, weight, and conducting foot checks. Participants cook and eat meals together that are consistent with AI cultures and traditions and discussion follows regarding the meal's ingredients, cost and availability, portion sizes, and relevance to diabetes and healthy weight maintenance. Educational sequences follow (which, consistent with CBPR methods/sequences, are planned and designed a priori according to participants' interests and wants), and take place in education and talking circles and a variety of lively activities consistent with AI cultures (e.g. traditional and modern music and drumming, chair dancing and aerobics, creative arts, impromptu theater/role plays). Instructional topics are similarly diverse, including: basic diabetes education, obesity and weight loss, foot care, stress management, exercise, family relationships, retinopathy, dental care, and resources to facilitate access to medical services and supplies (see table 3). FEDS evenings conclude with devoted time for informal sharing and support. These bi-weekly series are scheduled to last for three hours, but most participants arrive early and stay late.

Table 3 FEDS' session topics

Basic diabetes education and introduction
Diabetes in the AI community
Staying motivated with healthy habits
Dietary guidelines and portion sizes
Stress management and strategies
Fighting depression and despair
Exercise and physical activity (outdoors)
Exercise and physical activity (indoors)
Obesity and weight control
Foot care
Wound care
Blood glucose monitoring and control
Dental Care (teeth and gums)
Retinopathy/eye diseases
Keeping your kidneys healthy
Blood pressure and cholesterol
Heart disease and stroke
Gastroparesis
Neuropathy
Diabetes-related emergencies
Medical services and supplies
Working with your doctors
Family relationships/social support
Review/celebration of program

Pilot evaluation and testing

Although anecdotal reports of success have been common throughout the FEDS series, in 2008 we systematically followed participants through an entire program sequence to formally assess for quantitative change in key diabetes-relevant variables. Our guiding research question, which was developed and agreed upon by the citizen action group, was: Do participants in the FEDS program evidence change in their physical health, as measured by metabolic control (A1c), blood pressure, and weight? To answer this question, we tracked and analyzed data from baseline, 3- and 6- month follow-up (i.e. from the beginning to the conclusion of the program). Our efforts in doing this were reviewed and approved by the UMN's Institutional Review Board (IRB) and Human Research Protection Program (HRPP).

Consent processes followed standardized IRB/HRPP sequences in which participants were provided and oriented to the following: the project's purpose and who it was being conducted by; the project's (aforementioned) research question; background information justifying the project (i.e. statistics/data regarding diabetes prevalence and impact in the AI community); procedures for collecting data (i.e. blood samples for metabolic control, beam-scale for weight, pressure-cuff for blood pressure); risks (e.g. discomfort with finger-prick for blood collection, disclosure or discussion of personal or sensitive information); benefits (i.e. none guaranteed); data confidentiality; voluntary nature of participation; and contact information of investigators and a non-study-affiliated research subjects' advocate line. Discussions regarding informed consent, related questions, and procurement of signatures on hard-copy consent forms were conducted with each participant individually, and led by project members with appropriate IRB training and credentials.

Data collection was carried out collaboratively, as we recognized that AI community members would be more trusting of these processes if/as other AIs and their families were involved. Additionally, the citizen action group saw the process of collaborative data collection as both honoring the collective orientation of AI people (i.e. this is 'our' disease, this is 'our' challenge) while at the same time teaching and role-modeling good diabetes self-management skills. Although medical staff supervised these sequences to ensure that data were accurately measured and recorded, AIs and their family members collected each other's data during every FEDS meeting that was appropriate to collect (e.g. weight), and the providers/researchers collected data that was specialist-specific (e.g. blood samples for A1c assays; blood pressure). AI family community members, providers, and researchers were all present at the FEDS meetings in order to promote and sustain the idea of a partnership and co-creation of health. As each statistical analysis was run by the researchers, the citizen action group presented back the results to community members and discussed next steps for the FEDS program.

Pilot results

As outlined above, participants in the larger FEDS program include patients with diabetes, their families, and providers. Most patients (and their family members) identify themselves as AI, family members include patients' spouses, parents, and/or children, and providers represent a variety of disciplines (e.g. family physicians, nurses and nurse educators, dieticians, mental health providers). For the purposes of this pilot investigation, only study participants with type 2 diabetes who identified themselves as AI were included ($n = 36$). None were connected to (secondary to availability, uninsured-status and/or cost) primary or specialty care of any kind. None were taking any type(s) of diabetes-related medication (e.g. insulin). Most of the participants (79%) were female. Mean age was 55 years old, with a range of 22–80. Annual household incomes were distributed across the following range: <\$20 000 (68%); \$20 001–\$30 000 (18%); >\$30 000 (15%).

Measures

Weight was measured with a standard beam scale at baseline, 3 months, and 6 months follow-up (i.e. at the conclusion of the FEDS series).

Systolic and diastolic blood pressure was measured with an automated Omicron blood pressure cuff at baseline, 3 months, and 6 months follow-up.

Metabolic control (hemoglobin-A1c) was measured with capillary blood samples at baseline, 3 months, and 6 months follow-up. Assays were conducted through a UMN laboratory.

Statistical analysis

Data across pre-, mid- (3 months), and post- (6 months) intervention were analyzed using paired *t*-tests (see Table 4) to determine mean changes in participants' outcomes from baseline to 3 months, from 3 to 6 months, and overall change from baseline to 6 months. Analyses were conducted using SPSS/PASW (Statistical Package for the Social Sciences 2009). Pre-post effect sizes (Cohen's d) were calculated for matched-pairs data (Rosenthal 1984; Cohen 1988).

RESULTS

At 3-month follow-up, participants' average blood pressure was significantly reduced from baseline across both systolic (139.88–133.18; $p < 0.05$; $d = 0.47$) and diastolic (85.04–78.58; $p < 0.05$, $d = 51$) measures. Metabolic control (A1c) was significantly improved (6.99–6.53; $p < 0.05$, $d = 0.45$). No appreciable change in weight was noted ($p = \text{ns}$). At 6-month follow-up, participants' average weight loss had significantly improved, from 211.21 pounds at baseline to 196.86 pounds ($p < 0.05$; $d = 0.53$). No other measures were significantly improved from the earlier 3-month follow-up data collection. Significant *t*-values reported here had moderate effect sizes (Cohen 1988).

DISCUSSION

Several strengths of the FEDS project are important to note. First, the initiative employs a wide variety of techniques that

Table 4 Results of paired *t*-tests

	Time 1 (*T*1)	*T*1 → *T*2			*T*1 → *T*3		
	M (SD)	*M* (SD)	*t*	*p*	*M* (SD)	*t*	*p*
Weight	209.92 (45.04)	211.21 (44.19)	−0.323	0.748	196.86 (37.99)	2.67	0.012
Blood pressure							
Systolic	139.88 (12.32)	133.18 (12.50)	2.60	0.013	139.79 (7.28)	2.64	0.956
Diastolic	85.04 (12.73)	78.58 (6.31)	3.23	0.003	80.07 (5.18)	2.91	0.006
HbA1c	6.99 (1.11)	6.53 (0.69)	3.24	0.002	6.77 (0.75)	1.44	0.157

T1: baseline; T2: 3-month follow-up; T3: 6-month follow-up.

are sensitive to community participants' perspectives and worldviews, including talking and education circles, open-ended storytelling, smudging ceremonies, creative arts, dancing, music, and the sharing of community meals and fellowship. The culmination of these activities and methods – tapped through CBPR processes that collaboratively unite AI community members and western healthcare providers – reflect all members' respective viewpoints and voices. This is consistent with and contributes to existing (albeit sparse) CBPR literature and practice-recommendations that advocate the re-claiming of traditional ways and integrating them sensitively and purposefully with current scientific knowledge/education en route to better health (Burhansstipanov, Christopher and Schumacher, 2005; Carter et al. 1997; Hood et al. 1997; Davis and Reid 1999; Gilliland et al. 2002; Garwick and Auger 2003; Potvin et al. 2003; Castro et al. 2009; LaVeauz and Christopher 2009; O-Toole et al. 2009).

Second, the FEDS is carried out in the very context(s) that many clinical and AI community members seek to improve (i.e. urban-dwelling AIs who are struggling with diabetes and obesity). Over the course of its evolution and development, AI community- and healthcare provider members in the program defined their concerns and played active roles throughout and across the intervention and research, itself. Solutions to local-level problems were (are) developed and implemented through local-level resources. What was (is) produced is immediately relevant and fine-tuned to the local community; thus, translation of research findings into immediate practice was (is) enhanced. This work extends aforementioned literature through its advancing of knowledge into demographic groups in which most AIs reside (i.e. urban-dwelling contexts), but which have received the least attention across education – and direct intervention – research and care (Urban Indian Health Institute 2004; WhiteEagle 2005).

Finally, by identifying resources (personal and tangible) within the community that were previously untapped, participating members in the FEDS gained an increased sense of ownership in the initiative. They also endeavored (and continue to endeavor) to identify and develop consecutive generations of lay and clinical leaders, with each sequence of the FEDS including both veteran and new leaders/providers. The culmination of these efforts challenges the notion (frequently espoused by academic- and/or health-related fields and literature) that 'research' can only be carried out if/when it is first funded by monies secured by professionals and/or that programs/interventions can only be sustained if funded by monies that are secured in such a manner.

Indeed, the FEDS has functioned (and continues to function) with and without external funding. For example, intervention resources (such as food) have at times been provided through the collective contributions of participants, themselves, and at other times through external funding. Professionals' involvement has sometimes been funded by grant monies; other times it has been advanced through voluntary means and/or viewed as part of 'outreach' or 'community-oriented' components within existing professional job descriptions. The overall project's sustainability has thereby been enhanced because it is not dependent on external funding or the charisma and leadership of a single person (e.g. one community elder/leader, one university 'PI'). Although most existing literature reflects the investigatory efforts of professional researchers who conducted projects that they secured funding to create, advance, and/or evaluate, the FEDS does not function this way. This work supports the notion that both research and intervention/practice efforts can be advanced without depending on (or being delayed by) external funding. In fact, waiting for external funding is conceptually inconsistent with CBPR tenets insofar as to do so would be to rely on professionals' efforts in grant-writing (which would align with top-down, provider-driven sequences that are incompatible with genuine participatory approaches).

Limitations of the FEDS and its CBPR approach are also important to consider. First, the majority of our participants were women, which reflects a wider literature that has challenged the healthcare field to better and more effectively engage minority men in its efforts (e.g. Centers for Disease Control and Prevention 2009; National Institutes for Health 2010). As we advance our efforts to do this, future series of the FEDS will work to incorporate activities identified by our citizen action group as more attractive and appealing to AI men (e.g. drumming, field-trips, canoe-building, lacrosse).

Second, although our sample of AI participants closely resembles the tribal membership of the Twin Cities urban population, it is a small sample ($n = 36$) that was/has not been formally evaluated through a randomized-control trial design. Indeed, establishing the effectiveness of a program is generally (or at least preferably) carried out in a manner that includes large samples and a control/comparison group. However, it is our team's collective sense that a single group repeated-measures design was more appropriate at this point in our CBPR efforts because not allowing some members in the local AI community to participate in an initiative that is otherwise accessible to everyone is inconsistent with the community-oriented ('we') nature of AI people.

As we advance our efforts toward a solution to this problem (i.e. how to balance the scientific community's want for large-scale comparative studies vis-à-vis the local AI community's want for widespread and welcoming inclusion in a community resource), our team is working to increase and extend the FEDS program locally (i.e. raising project sample size(s)) and to compare its participants through electronically matched comparison groups of more geographically distant AI patients receiving standard-care through integrated medical records systems that are available to us through the Minnesota Academy of Family Physicians (regionally) and the Electronic Primary Care Research Network (nationally). Our (and others') future conduct of research in this way will advance and honor the competing interests of local AI communities and the broader scientific community simultaneously.

In regard to the replicable or generalizable nature of the FEDS intervention, it is important to remember that CBPR is primarily oriented to producing change in a local community that is comprised of a unique and complex mix of contextual components. Abstract generalizability, once assumed to personify a study's scientific merit, is de-emphasized in CBPR as other criteria (e.g. the generation of local and usable knowledge) are offered in its place (Minkler 2002; Mendenhall and Doherty 2005). What is (or will be found to be) generalizable, then, may not be the FEDS program in its exact form – but in its participatory process of engaging professionals and community members in partnership to improve the health and lives of AI people who live with diabetes.

To this end (i.e. to honor the scientific community's high regard for generalizability and local relevancy-to-context via CBPR simultaneously), we are now constructing a FEDS field manual that: (i) outlines the current context of diabetes as an epidemic across AI communities (i.e. summaries existing epidemiological and practice/intervention research literature); (ii) describes CBPR and the Citizen Health Care Model and approach; (ii) summarizes the FEDS and its learnings (including the program's early history and evolution, collaboration between community members and healthcare providers, process and content of meetings, evaluative methods/findings); and (iv) exemplifies ongoing efforts in sustainability (across resource and leadership foci). Urban areas in the USA with the highest documented populations of AIs include: Anchorage, AK; Tulsa, OK; Oklahoma City, OK; Albuquerque, NM; Green Bay, WI; Tacoma, WA; Minneapolis, MN; Tucson, AZ; Spokane, WA; and Sacramento, CA (Urban Indian Health Institute 2004; Urban Indian Health Commission 2007). AI elders and community leaders across several of these cities have already expressed interest to us in learning more about the FEDS, and their ability to realize efforts in creating similar community-based diabetes programs in partnership with local medical and mental health providers and institutions will be greatly increased through the use of our forthcoming field manual.

CONCLUSION

As health professionals and AI communities work together to transcend conventional top-down, service-delivery approaches to care, CBPR is beginning to show promise as a way to partner contemporary biomedical knowledge with the lived-experience, wisdom, and customs of Indigenous people. The FEDS represents such as partnership, as it was collaboratively designed and implemented by local AI elders/leaders in a Midwestern United States community and western providers/researchers affiliated with the University of Minnesota Medical School. Through its integration of traditional practices and ways (e.g. talking circles, ceremonial dancing) with up-to-date knowledge/education about health, and through its targeting of the most vulnerable facets (i.e. urban-dwelling) of AI people, the FEDS has come to represent an empowering resource that neither the AI- nor professional/research- community could have developed on its own.

Participants in the FEDS program have evidenced significant improvement in their health across weight, blood pressure (diastolic and systolic), and metabolic control (A1c) measures. These findings extend existing literature and previous work that advocates for the careful integration of cultural habitudes, traditions, and mores into health-related education and interventions (generally), and expands this understanding into the urban-dwelling contexts in which most – and the most vulnerable of – AIs reside (specifically). Future practice and collaborative research endeavors should continue this course, and thereon actively engage/involve healthcare professionals with community members (however defined) in the creation and implementation of education/outreach endeavors. Further, the FEDS challenges us to do this with or without external funding, as tapping local resources, wisdom, and expertise in communities who are invested in working to improve their members' health is something that can (and should) rest on the distributed energies of all involved. Programs established this way are likely to be more sustainable over time because they are owned and operated by the communities in which they are positioned, as opposed to functioning on monies secured by professionals, which tend to be temporary and variable.

Future research regarding the FEDS and related efforts must incorporate more effective methods of engaging men. Integrating and including activities recognized to be attractive and appealing to AI males, such as drumming, field-trips, canoe-building, and/or lacrosse, is indicated. Further, said research and related efforts must work to address the problem of how to balance the scientific community's want for large-scale comparative studies vis-à-vis the local community's want for widespread and welcoming inclusion in a community resource. Comparing intervention participants through electronically matched comparison groups is a promising solution, insofar as patients geographically distant from the intervention (but similar in key demographics) are accessible through integrated medical records systems that are available through practice-based research networks (e.g. Minnesota Academy of Family Physicians, Electronic Primary Care Research Network (nationally)). Additionally, future work in simultaneously honoring the scientific community's high regard for generalizability with CBPR projects' want for local relevancy and personalizing of interventions can be rejoined through the construction of field manuals that outline guiding principles and processes of the CBPR work (which can be generalized). As described above, several AI leaders/elders and health providers/researchers positioned in other US urban areas are now posed to do this as they advance local versions of the FEDS program.

Finally, it is worth returning to the greater vision for FEDS: to create a model of health-care, education, and outreach in the AI community as work by and for its citizens, with all stakeholders – including elders/leaders, patients and their families, physicians and other providers – working as active contributors. Everyone involved in the FEDS shows a sense of participating in something of profound significance, and they are energized by this broader vision. At an early meeting when the first author maintained that the FEDS was (is) advancing change in how health is embraced in the local AI community, one of the elders interrupted him and said, 'This is for all of our people – here in Minnesota and across the country, and even the world.' As future efforts in FEDS and related CBPR initiatives proceed, this vision of transforming health will serve as a sustainer of energy and commitment in the face of a formidable but inspiring mission.

REFERENCES

Agency for Healthcare Research and Quality. 2004. *Community-based participatory research: Assessing the evidence*. Rockville, MD: AHRC.

American Indian Policy Center. 2010. *Introductory data on American Indians*. St Paul, MN: Center for Urban and Regional Affairs, University of Minnesota.

Baum Fran, Colin MacDougall and Danielle Smith. 2006. Participatory action research. *Journal of Epidemiology and Community Health* 60: 854–7.

Bell John, Gail Cheney, Cindy Hoots, Elaine Kohrman, Jesse Schubert, Lisa Stidham and Scott Traynor. 2004. *Comparative similarities and differences between action research, participative research, and participatory action research*. Seattle, WA: Antioch University Seattle.

Berge Jerica, Tai Mendenhall and William Doherty. 2009. Using community-based participatory research to target health disparities. *Family Relations* 58: 475–88.

Bindon James and Paul Baker. 1997. Bergmann's rule and the thrifty genotype. *American Journal of Physical Anthropology* 104: 201–10.

Bogart Laura and Kimberly Uyeda. 2009. Community-based participatory research: Partnering with communities for effective and sustainable behavioral health interventions. *Health Psychology* 28: 391–3.

Bradbury Hilary and Peter Reason. 2003. Action research: An opportunity for revitalizing research purpose and practices. *Qualitative Social Work* 2: 155–75.

Braithwaite Rhonda, Sarah Cockwill, Martin O'Neill and Deanne Rebane. 2007. Insider participatory action research in disadvantaged post-industrial areas: The experiences of community members as they become community based action researchers. *Action Research* 5: 61–74.

Brugge Doug, Edna Rivera-Carrasco, Jean Zotter and Alice Leung. 2010. Community-based participatory research in Boston's neighborhoods: A review of asthma case examples. *Archives of Environmental and Occupational Health* 65: 38–44.

Burhansstipanov Linda, Suzanne Christopher and Ann Schumacher Sr. 2005. Lessons learned from community-based participatory research in Indian country. *Cancer Control: Cancer, Culture and Literacy* 12 (Supplement 2) 70–6.

Byrne Elaine and Sundeep Sahay. 2006. Participatory design for social development: A South African case study on community-based health information systems. *Information Technology for Development* 13: 71–94.

Cammarota Julio and Michelle Fine. 2008. *Revolutionizing education: Youth participatory action research in motion*. New York: Routledge.

Carter Janette, Susan Gilliland, Georgia Perez, Sarah Levin, Brenda Broussard, Lorraine Valdez, Leslie Cunningham-Sabo and Sally Davis. 1997. Native American Diabetes Project: Designing culturally relevant education materials. *The Diabetes Educator* 23: 133–4.

Castro Sarah, Mary O'Toole, Carol Brownson, Kimberly Plessel and Laura Schauben. 2009. A diabetes self-management program designed for urban American Indians. *Public Health Research, Practice, and Policy* 6: 1–8.

Centers for Disease Control and Prevention. 2009. Diabetes data and trends. http://www.cdc.gov/diabetes/statistics/prev/national/figpersons.htm (accessed on September 13, 2010).

Centers for Disease Control and Prevention. 2009. Men's health. http://www.cdc.gov/nchs/hus/men.htm (accessed on September 13, 2010).

Chateau-Degat Marie-Ludivine, Daria Pereg, Grace Egeland, Evert Nieboer, Yv Bonnier-Viger, Elhadji Laouan-Sidi, David Dannenbaum and Eric Dewailly. 2009. Diabetes and related metabolic conditions in an aboriginal Cree community of Quebec, Canada. *Canadian Journal of Diabetes* 33: 156–62.

Chavez Vivian, Bonnie Duran, Quniton Baker, Magdalena Avila and Nina Wallerstein. 2003. The dance of race and privilege in community-based participatory research. In *Community based participatory research for health*, eds Meredith Minkler and Nina Wallerstein, 81–97. San Francisco, CA: Jossey-Bass.

Classen Lauren, Sally Humphries, John Fitzsimons, Susan Kaaria, Jose Jimenez, Fredy Sierra and Omar Gallardo. 2008. Opening participatory spaces for the most marginal: Learning from collective action in the Honduran hillsides. *World Development* 36: 2402–20.

Cohen Jacob. 1988. *Statistical power analysis for the behavioral sciences*, 2nd edn. Hillsdale, NJ: Erlbaum.

Cornwall Andrea and Rachel Jewkes. 1995. What is participatory research? *Social Science Medicine* 41: 1667–76.

Davis Sally and Raymond Reid. 1999. Practicing participatory research in American Indian communities. *American Journal of Clinical Nutrition* 69: 755S–9S.

Doherty William and Tai Mendenhall. 2006. Citizen health care: A model for engaging patients, families, and communities as co-producers of health. *Families, Systems & Health* 24: 357–62.

Doherty William, Tai Mendenhall and Jerica Berge. In press. The families & democracy and Citizen Health Care Project. *Journal of Marital and Family Therapy*.

Edwards Karen, Carrielynn Lund, Steven Mitchell and Neil Anderson. 2008. Trust the process: Community-based research partnerships. *Journal of Aboriginal and Indigenous Community Health* 6: 187–99.

Garwick Ann and Sally Auger. 2003. Participatory action research: The Indian Family Stories Project. *Nursing Outlook* 51: 261–6.

Gilliland Susan, Stanley Azen, Georgia Perez and Janet Carter. 2002. Strong in body and spirit: Lifestyle intervention for Native American adults with diabetes in New Mexico. *Diabetes Care* 25: 78–83.

Gone Joseph. 2006. Researching reservations: Response and responsibility in an American Indian community. *American Journal of Community Psychology* 37: 333–40.

Gracey Michael and Malcolm King. 2009. Indigenous health part 1: Determinants and disease patterns. *The Lancet* 374: 65–75.

Hampshire Amanda, Mitch Blair, Nicola Crown, Anthony Avery and Idris Williams. 1999. Action research: A useful method of promoting change in primary care? *Family Practice* 16: 305–11.

Heron John and Peter Reason. 2001. The practice of co-operative inquiry: Research 'with' rather than 'on' people. In *Handbook of action research: Participative inquiry and practice*, eds Peter Reason and Hillary Bradbury, 179–88. London: Sage.

Hood Virgina, Kelly Benson, Charlene Martinez and Roger Secker-Walker. 1997. A Native American community initiative to prevent diabetes. *Ethnicity and Health* 4: 277–88.

Indian Health Service. 2005. *Trends in Indian health*. Rockville, MD: US Department of Health and Human Services.

Jiang Luohua, Yvette Roubideaux, Jeanette Beals, Spero Manson and Nancy Witesell. 2008. Stress burden and diabetes in two American Indian reservation communities. *Diabetes Care* 31: 427–9.

Kahn Wasqas and Imran Khan. 2009. Solutions to issues of equity in primary healthcare for Aboriginal people living in Canada. *Hypothesis* 8: 1–6.

Kelly James, Lynne Mock and Darius Tandon. 2001. Collaborative inquiry with African American community leaders: Comments on a participatory action research process. In *Handbook of action research*, eds Peter Reason and Hilary Bradury, 348–55. London: Sage.

Keltner Bette, Francis Kelley and Debra Smith. 2004. Leadership to reduce health disparities: A model for nursing leadership in American Indian communities. *Nursing Administration Quarterly* 28: 181–90.

Kemmis Stephen and Robin McTaggart. 2000. Participatory action research. In *Handbook of qualitative research*, eds Norman Denzin and Yvonna Lincoln, 567–605. Thousand Oaks, CA: Sage.

King Gail. 2004. Type II diabetes: The modern epidemic of American Indians in the United States. http://www.as.ua.edu/ant/bindon/ant570/Papers/King/king.htm (accessed on September 13, 2010).

King Malcolm, Alexandra Smith and Michael Gracey. 2009. Indigenous health part 2: The underlying causes of the health gap. *The Lancet* 374: 76–85.

Kramer Josea. 1992. Health and aging of urban American Indians. *Western Journal of Medicine* 157: 281–5.

LaVeauz Deborah and Suzanne Christopher. 2009. Contextualizing CBPR: Key principles of CBPR meet the indigenous research context. *Journal of Aboriginal and Indigenous Community Health* 7: 1–25.

LeMaster Pamela and Cathleen Connell. 1994. Health education interventions among Native Americans: A review and analysis. *Health Education Quarterly* 21: 521–38.

Lewin Kurt. 1946. Action research and minority problems. *Journal of Social Issues* 2: 34–46.

Lewis Kristi, David Sallee, Judith Trumbo and Kathryn Janousek. 2010. Use of community-based participatory research methods in adults' health assessment. *Journal of Applied Psychology* 40: 195–211.

Lindsey Elizabeth and Liza McGuinness. 1998. Significant elements of community involvement in participatory action research: Evidence from a community project. *Journal of Advanced Nursing* 28: 1106–14.

Ludema James, David Cooperrider and Frank Barrett. 2001. Appreciative inquiry: The power of the unconditional positive question. In *Handbook of action research*, eds Peter Reason and Hilary Bradury, 189–99. London: Sage.

Mendenhall Tai. 2002. Partners in diabetes: The process and evolution of a democratic citizenship initiative in a medical context. PhD diss., University of Minnesota.

Mendenhall Tai and William Doherty. 2005. Action research methods in family therapy. In *Research methods in family therapy*, 2nd edn, eds Fred Piercy and Douglas Sprenkle, 100–17. New York, NY: Guilford Publications.

Mendenhall Tai and William Doherty. 2007. The ANGELS (A Neighbor Giving Encouragement, Love and Support): A collaborative project for teens with diabetes. In *The therapist's notebook for family healthcare*, eds Deanna Linville and Katherine Hertlein, 56–70. New York: Apex Press.

Meyer Julienne. 2000. Using qualitative methods in health related action research. *British Medical Journal* 320: 178–81.

Minkler Meredith. 2002. Introduction and overview. In *Community organizing and community building for health*, ed. Meredith Minkler, 3–19. New Brunswick, NJ: Rutgers University Press.

Minkler Meredith and Nina Wallerstein. 2003. Introduction to community-based participatory research. In *Community-based participatory research for health*, eds Meredith Minkler and Nina Wallerstein, 3–26. San Francisco, CA: Jossey Bass.

Minkler Meredith, Angela Blackwell, Mildred Thompson and Heather Tamir. 2003. Community-based participatory research: Implications for public health funding. *American Journal of Public Health* 93: 1210–3.

National Diabetes Information Clearing House. 2002. Diabetes in American Indians and Alaska Natives. http://diabetes.niddk.nih.gov/dm/pubs/americanindian/#24 (accessed on September 13, 2010).

National Heart Lung and Blood Institute. 2004. National high blood pressure education program (NHBPEP). http://www.nhlbi.nih.gov/health/prof/heart/hbp/bpmeasu.pdf (accessed on September 13, 2010).

National Institute of Diabetes and Digestive and Kidney Diseases. 2007. National diabetes statistics. http://diabetes.niddk.nih.gov/DM/PUBS/statistics/#allages (accessed on September 13, 2010).

National Institutes for Health. 2010. Health promotion among racial and ethnic minority males (R01). http://grants.nih.gov/grants/guide/pa-files/PA-07-422.html#PartII (accessed on September 13, 2010).

Oster Richard and Ellen Toth. 2009. Differences in the prevalence of diabetes risk-factors among First Nation, Metis and non-Aboriginal adults attending screening clinics in rural Alberta, Canada. *Rural and Remote Health* 9, June 1. http://www.rrh.org.au/articles/subviewnew.asp?ArticleID=1170 (accessed on September 13, 2010).

Pan American Health Organization. 2004. *Participatory evaluation of healthy municipalities: A practical resource kit for action* (field-testing version). Washington, DC: Pan American Health Organization.

Ponchilla Susan. 1993. The effect of cultural beliefs on the treatment of native peoples with diabetes and visual impairment. *Journal of Visual Impairment and Blindness* 93: 333–7.

Potvin Louise, Margaret Cargo, Alex McComber, Treena Delormier and Ann Macaulay. 2003. Implementing participatory intervention and research in communities: Lessons from the Kahnawake Schools Diabetes Prevention Project in Canada. *Social Science Medicine* 56: 1295–305.

Pyrch Timothy. 2007. Participatory action research and the culture of fear: Resistance, community, hope and courage. *Action Research* 5: 199–216.

Pyrch Timothy and Maria Castillo. 2001. The sights and sounds of Indigenous knowledge. In *Handbook of action research*, eds Peter Reason and Hilary Bradury, 379–85. London: Sage.

Rahman Anisor and Orlando Fals-Borda. 1991. *A self-review of PAR in action and knowledge: Breaking the monopoly with participatory action research*. London: Intermediate Technology Publications.

Rhoades Dorothy and Dedra Buchwald. 2003. Hypertension in older urban Native-American primary care patients. *Journal of the American Geriatrics Society* 51: 774–81.

Roberts Henry, Ruth Jiles, Ali Mokdad, Gloria Beckles and Nilka Rios-Burrows. 2009. Trend analysis of diagnosed diabetes prevalence among American Indian/Alaska Native young adults – United States, 1994–2007. *Ethnicity & Disease* 19: 276–9.

Rosenthal R. 1984. *Meta-analytic procedures for social research*. Beverly Hills, CA: Sage.

Sahmoun Abe, Mary Markland and Steven Helgerson. 2007. Mental health status and diabetes among Whites and Native Americans: Is race an effect modifier? *Journal of Health Care for the Poor and Underserved* 18: 599–608.

Scharff Darcell and Katherine Mathews. 2008. Working with communities to translate research into practice. *Journal of Public Health Management Practice* 14: 94–8.

Schulz Amy, Barbara Israel, Edith Parker, Murlisa Lockett, Yolanda Hill and Rochelle Wills. 2003. Engaging women in community-based participatory research for health: The east side village health worker partnership. In *Community based participatory research for health*, eds Meredith Minkler and Nina Wallerstein, 293–315. San Francisco, CA: Jossey-Bass.

Statistical Package for the Social Sciences (SPSS/PASW). 2009. Statistical Package for the Social Sciences. http://www.spss.com.

Steckler Allan, Becky Ethelbah, Catherine Martin, Dawn Stewart, Marla Pardilla, Joel Gittelsohn, Elaine Stone, David Fenn, Mary Smyth and Maihan Vu. 2002. Lessons learned from the Pathways process evaluation. In *Process evaluation for public health interventions and research*, eds Allan Steckler and Laura Linnan, 268–87. San Francisco, CA: Jossey-Bass.

Strickland CJune. 2006. Challenges in community-based participatory research implementation: Experiences in cancer prevention with Pacific Northwest American Indian tribes. *Cancer Control* 13: 230–6.

Taylor Timothy. 1988. Health problems and use of services at two urban American Indian clinics. *US Department of Health and Human Services/Public Health Reports* 103: 88–95.

Tobin Michael. 2000. Developing mental health rehabilitation services in a culturally appropriate context: An action research project involving Arabic-speaking clients. *Australian Health Review* 23: 177–84.

Torre Maria and Michelle Fine. 2005. Don't die with your work balled up in your fists: Contesting social injustice through participatory research. In *Urban girls revisited: Building strengths*, eds Bonnie Ross Leadbeater and Niobe Way, 221–40. New York: New York University Press.

United States Census Bureau. 2010. American Indian and Alaska Native data and links. http://factfinder.census.gov/home/aian/index.html (accessed on September 13, 2010).

Urban Indian Health Commission. 2007. Invisible tribes: Urban Indians and their health in a changing world. http://www.uihi.net/Public/UIHC%20Publications/UIHC_Report_Final.pdf (accessed on September 13, 2010).

Urban Indian Health Institute. 2004. *The health status of urban American Indians and Alaska Natives: An analysis of select vital records and census data sources*. Seattle, WA: Urban Indian Health Institute.

Wallerstein Nina and Bonnie Duran. 2006. Using community-based participatory research to address health disparities. *Health Promotion Practice* 7: 312–23.

Ward Karen and JordanS Trigler. 2001. Reflections on participatory action research with people who have developmental disabilities. *Mental Retardation* 39: 57–9.

WhiteEagle Shelia. 2005. *Greater twin-cities united way: Addressing gaps in service*. St Paul, MN: Saint Paul Area Council of Churches/Department of Indian Work.

Wilson Val, Aileen Ho and Raelene Walsh. 2007. Participatory action research and action learning: Changing clinical practice in nursing handover and communication. *Journal of Children's and Young People's Nursing* 1: 85–92.