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## Lessons Learned in Conducting Community Participatory School-Based Health Research on an American Indian Reservation

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### Abstract

**Background:** Describing lessons learned from using a community-based participatory research (CBPR) approach to conduct school-based child health research in a tribal community is an important contribution to the literature.

**Objectives:** To identify how CBPR principles shaped the process of conducting a school-based child health intervention, and to describe lessons learned.

**Methods:** The study evaluates how CBPR principles guided a mixed-methods, school-based child health intervention to increase physical activity (PA).

**Results:** Nine key lessons are identified, associated with CBPR principles.

**Conclusions:** This information can help researchers understand how to successfully navigate the challenges and opportunities of conducting CBPR-guided research in the context of a small, short-term project, including leadership turnover, multiple Institutional Review Board (IRB)s, and study design approaches amidst schools policy changes. Collectively, understanding the lessons learned through the perspective of CBPR principles may help others conduct meaningful research with schools and children in tribal communities.

### Keywords

American Indian; Community-Based Participatory Research; Tribally Based Research; School-Based Research

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School-based research is time-consuming, difficult, and rewarding. Existing literature addresses “lessons learned” from conducting school-based research in the general population. Some commonly reported lessons to conduct successful school-based research are: including the community, school, and parents in all aspects<sup>1–8</sup>; contending for school space<sup>9</sup>; overcoming school schedule or academic conflicts<sup>5,9–12</sup>; communicating with school personnel<sup>9,13</sup>; and overcoming administrative hurdles.<sup>2,14</sup> Although the same issues may exist in tribal communities, a CBPR approach provides strategies and principles to strengthen school-based research approaches in this setting. For example, CBPR approaches may help alleviate mistrust of outsiders<sup>15</sup> associated with historical trauma,<sup>16</sup> while reinforcing strengths that lessen the effects of colonialism and enhance healing and resiliency.<sup>16</sup>

To date, CBPR studies conducted in tribal settings have mostly included adults.<sup>17–23</sup> Existing studies focusing on child health include the Indian Family Wellness Project,<sup>24,25</sup> Pathways,<sup>26</sup> Zuni Diabetes Prevention Program,<sup>27</sup> Kahnawake Schools Diabetes Prevention Project,<sup>28,29</sup> and Journey to Native Youth Health Program.<sup>30</sup> Of these, two included third through sixth graders,<sup>26,30</sup> and most addressed obesity and diabetes prevention, while one addressed tribal research infrastructure development.<sup>24</sup> Among these studies, similar strategies were used to initiate the research process; all conducted a formative assessment and established community relationships. In contrast, strategies for intervention structure and delivery were unique. The Indian Family Wellness study developed a parent-child curriculum to enhance parenting practices.<sup>24</sup> The Pathways study featured four intervention arms that consisted of healthful curriculum, physical education, family, and school nutrition.<sup>26</sup> The Zuni Diabetes Prevention Program also featured four intervention arms that consisted of supportive social networks, teen wellness facility, diabetes education, and food intake.<sup>27</sup> The Kahnawake Schools Diabetes Prevention Project included school-based activities and more than 63 community-based activities.<sup>28</sup> The Journey to Native Health Program included nine group sessions on health.<sup>30</sup> None of the previous school-based work has been done to increase child PA during recess.

This article describes the process of conducting a school-based intervention to increase child PA during recess using CBPR principles on an American Indian (AI) reservation. Study outcomes are presented elsewhere<sup>31,32</sup> and discussed briefly below. This project was unique in that it involved a small, single-component intervention implemented without significant external resources. The research team was led by a tribally enrolled doctoral student from a Montana tribal community. Further, the research team included a tribally enrolled faculty supervisor who was also a member of the tribal community. Although it was unclear if the research partnership would proceed after the study was completed, the partners discussed the possibility of ongoing work. Despite the unique conditions and constraints, the research team was able to use CBPR principles while conducting the study.

## CPBR PRINCIPLES

In 1998, Israel et al.<sup>33</sup> proposed eight guiding principles for the CBPR approach (Table 1). In 2009, LaVeaux and Christopher<sup>34</sup> adapted these key CBPR principles to tribal communities. These adaptations to the original CBPR principles can be helpful for individuals conducting research with tribal communities.

The purpose of this article is to describe lessons learned conducting a school-based intervention, and how lessons relate to the original CBPR principles described by Israel et al.<sup>33</sup> and, where applicable, to the tribally adapted CBPR principles described by LaVeaux and Christopher.<sup>34</sup> The principles mentioned throughout the text are those described by Israel et al.<sup>33</sup> and denoted by (# CBPR Principle).

## LESSONS LEARNED

### Establishing the Community-Academic Partnership

In the fall of 2010, the research team (consisting of University of Montana faculty and a doctoral student) initiated several meetings with key stakeholders on an AI reservation to discuss partnering on a school-based intervention (Figure 1). Stakeholders included tribal council members, the tribal health department (THD) director, schoolteachers, and school administrators. The research team was transparent in communicating that the project was, in part, driven by the doctoral student's research interest of studying the effect of increasing PA on decreasing risk of childhood obesity. The strict PA focus is why the study did not include investigating nutrition, screen time, or sleep. Overall, the stakeholders expressed enthusiasm for the topic area since children's lack of PA at school was a strong concern. Additionally, stakeholders expressed strong support for helping the student complete his doctoral degree requirements so that he could lead other projects to help address health disparities in tribal communities, including on his own reservation. From 2006 to 2016, AIs accounted for less than 1% of all doctoral degrees conferred in the United States.<sup>35</sup> Thus, support for the student's training is a unique example of the CBPR principle promoting co-learning and capacity building (#5); the student was viewed as an AI resource whose skill development was valued by the stakeholders.

Developing relationships is foundational to any school-based research, especially when working in a tribal community.<sup>2,4,6,7,9,10,13,14,36-39</sup> Establishing relationships and obtaining letters of support helped the research team obtain buy-in from "gatekeepers,"<sup>34</sup> such as the tribal council, school board, school administration, and community members. Developing successful relationships with key stakeholders and community members is an example of the CBPR principle of facilitating collaborative partnerships in all phases of the research (#3).

A Tribal Resolution was adopted by the tribal council. This guided project protocol and stipulated that identities must remain anonymous (i.e., participants, communities, and the reservation). Additional recommendations of the resolution suggested IRB oversight, and that resulting data would be tribal property disseminated only with tribal consent. The process followed by the research team recognized the tribe as a unit of identity, which relates to the CBPR principle of recognizing the community as a unit of identity (#1).

The research team employed a sequential mixed-methods approach; the study design and results are reported elsewhere<sup>31,32</sup> and briefly summarized here. In the formative phase, the research team collaborated with THD staff to recruit families to focus groups, where they discussed strategies to increase child PA. Results showed that families supported structured recess.<sup>32</sup> Findings were disseminated at a local event; at the event, community members expressed additional support for structured recess activities. This process relates to the CBPR principle of disseminating findings and knowledge gained to all partners (#8). The research team then designed a recess intervention. The intervention design was presented to the THD director, the school superintendent and principal, and the school board; support was unanimous. A structured recess intervention was implemented to increase child PA, using an ecological framework to encompass the individual (e.g., child), his or her immediate contexts (e.g., instructors, other school children), and the larger social spheres or institutions

in which they are embedded (e.g., school playground). This was an example of the CBPR principle addressing health from an ecological perspective (#7). Briefly, the recess intervention consisted of dividing the school playground into three zones: one containing painted lines on the playground for hopscotch, nine-square, and four-square; one containing bi-weekly facilitated games; and the third containing playground equipment. Results showed that providing playground equipment elicited the highest PA, and there was no difference in PA between facilitated/non-facilitated games.<sup>31</sup>

The remainder of this article describes lessons learned in the context of CBPR principles. To our knowledge, no other studies present lessons learned from using a CBPR approach to collaborate with school and community entities to develop and implement a school-based intervention in a tribal community. The following information may prove useful to others conducting small, school-based projects with tribal communities.

### **School-Based Research in Tribal Communities May Require Approvals Outside of the School System**

During the formative phase of the study, meetings were held with the THD, tribal council, the Indian Education Committee, and school administration to establish relationships and obtain study support. These meetings occurred prior to IRB submission. While this process delayed formative data collection, establishing relationships were critical to study success. Talking to community members about the project strengthened relationships with multiple tribal entities and brought together perspectives representing communities from across the reservation. Thus, this process relates to the CBPR principle of building on strengths and resources within the community (#2).

During the intervention phase, the established relationships allowed the research team to work with school personnel, most notably the administrative assistant, who assisted in all aspects of intervention implementation. For instance, the administrative assistant sent an email description of the intervention to all teachers that also helped gain permission to present the study to their classrooms. Collectively, this enhanced teachers' understanding of the intervention and also increased receptiveness to allocating class time to data collection. This process relates to the CBPR principle of involving a cyclical and iterative process (#6) in that relationship building with teachers at the school was an ongoing.

The lesson learned is school-based research in tribal communities may require tribal approvals outside of the school system. Approval was obtained from the THD, tribal council, and Indian Education Committee. Securing these approvals was instrumental for cooperation and collaboration with the school superintendent and principal. This contrasts working with non-tribal communities, especially large urban communities that may only require school board and administrative approvals.<sup>2,6,13</sup>

### **Prepare for Leadership Turnover**

During the formative phase, the school principal was leaving the position and the superintendent was interim. It was unethical to proceed with research during interim leadership. Therefore, the research team waited to build relationships with—and present the intervention study design to—the new principal and superintendent. This delayed

intervention implementation until the following school year. Leadership turnover is a tribally specific CBPR principle identified by LaVeaux and Christopher.<sup>34</sup> The project could have been jeopardized had the research moved forward without incoming administrative support. Partnerships with the current school leadership were maintained throughout the study, thus adhering to the CBPR principle of facilitating collaborative partnerships in all phases of the research (#3).

The lesson learned is that leadership turnover in tribal communities may consist of key school leaders that can impact the outcome of a study. This relates to the CBPR principle of integrating knowledge and action for the mutual benefit of all partners (#4). The extensive time spent developing relationships with study partners helped establish credibility and garner support from the incoming administration.

### **Partner with a “Champion” in the Community for Recruitment Activities**

Gaining entry into the school and community was a challenging and lengthy process. To move the study forward, the doctoral student attempted to recruit families to a meeting by posting flyers at the community grocery stores, schools, and the post office. There was also an announcement on the community website, and information was shared through word of mouth by THD staff. At the first meeting, no families showed up.

This failure reminded the team of the importance of following the CBPR principle to include partners in all aspects of the project, especially recruitment (#3). The research team regrouped and partnered closely with THD staff to recruit families for a second meeting. Despite this set back, the relationship with the THD staff was strengthened as they took the lead and rescheduled the meeting. Although similar recruitment strategies were used, this time the information came from THD staff and not outside researchers.<sup>10</sup> This recognized the THD as an important community resource, highlighting the CBPR principle of building on existing strengths and resources (#2). Twenty families attended the second meeting, which was encouraging as other studies have reported low parental participation in recruitment efforts.<sup>2</sup> From this point forward, word spread quickly and families were excited to get involved. Formative phase participants ensured that the community voice informed the intervention design, which relates to the CBPR principle of promoting a co-learning and empowering process that attends to social inequalities (#5).

School-based interventions note the importance of parental, school, and community engagement for successful recruiting.<sup>1,3,7,36</sup> The lesson learned regarding recruitment is that a “champion” does not always come from within the school. In this case, the “champions” worked for the THD, and a community advocate working directly with families across the reservation. They not only had school district credibility, but personal family relationships. Other studies report working with a champion within the school,<sup>10</sup> but non-school champions may also be critical to success.

### **Reporting Results back to the Community Builds Capacity**

Formative methods have been successful for intervention development<sup>2</sup> and establishing relationships.<sup>36</sup> Research shows that if children are not involved in the planning, or if their interest is not captured, the intervention is unlikely to succeed.<sup>4,8</sup> Six focus groups were

conducted with adults and children to understand barriers and strategies to increase PA during the school day.<sup>32</sup> The research team disseminated the focus group findings to community outlets to obtain feedback and discuss intervention ideas. The school principal, teachers, the THD director, and community members attended the meeting. The group agreed on structured PA during recess because 1) it did not interfere with the school day schedule; 2) no “new” space needed to be created; and 3) teachers did not have to escort students to the activity.<sup>9,10</sup> Others have reported the importance of working with community members during intervention development,<sup>9,14,37</sup> which relates to the CBPR principles of integrating knowledge and action for mutual benefit of all partners (#4) and disseminating findings and knowledge gained to all partners (#8).

A lack of playground equipment (e.g., monkey bars, swings, slides) was a recurring theme among the formative findings. When this theme was discussed, the THD director informed the group that playground equipment was available, but community leaders needed to install it. Although this information had been previously communicated, installation never occurred. This meeting helped to facilitate communication between the THD and community leaders, which relates to the CBPR principle of building on strengths and resources within the community (# 2).

Although playground equipment installation caused a study design dilemma described elsewhere in this article, dissemination efforts enhanced support and built capacity between the THD director (who provided the playground equipment) and community leaders (who installed the equipment). Disseminating research findings throughout the study (not just at the conclusion) relates to the CBPR principle of involving cyclical and iterative processes (#6), and the CBPR principle of benefiting all parties involved (#4).

During the meeting, the principal learned about the study first hand. Gaining this support proved vital when developing a relationship with the new superintendent. The lesson learned is reporting results back to community leaders can address needs and build capacity by facilitating discussions to address needs. Other studies discuss a “shared vision” between stakeholders and the research team.<sup>14</sup> Installing playground equipment became a “shared vision” for all.

### **IRB Approval for Studies Conducted with Tribal Communities Can Be Complex**

Obtaining IRB approval to conduct research with tribal communities can be challenging. Per the Tribal Resolution, the research team was instructed to submit to a regional tribal IRB. Per the institutional guidelines, university IRB approval was an additional requirement. Despite lengthy conversations with tribal and university IRBs, it remained unclear which IRB had authority over the project. Prior research emphasizes the importance of working with an IRB that understands the CBPR process<sup>2</sup> and for this research, familiarity with tribal knowledge. Therefore, authority was ceded by the university and delegated to the regional tribal IRB.

The conversations opened new lines of communication between the two IRBs regarding authority over tribally focused research. This process was unique, and the IRBs had not previously collaborated. This process acquainted the IRB chairs personally, so that future

issues could be managed quickly. This experience provides a road map for future investigators navigating tribal and university IRBs, and relates to the CBPR principle of promoting a co-learning and empowering process that attends to social inequalities (# 5).

This IRB experience was arguably unique. The lesson learned when working with multiple IRBs is to collaboratively discuss the project and determine which entity should be delegated authority. Accordingly, because it is important to receive oversight from an entity that understands the CBPR process<sup>2</sup> and is familiar with tribal knowledge, it is appropriate for authority to be granted to the tribal IRB. Finally, researchers should be prepared for a lengthy IRB process,<sup>36</sup> which is discussed elsewhere in this article.

### **Plan for Extended Timelines and Be Flexible with the Process**

The formative findings were reported to the community in the fall of 2012. The recess intervention was designed and presented to the school administration for approval in the winter of 2012–2013. This process relates to the CBPR principle of disseminating findings and knowledge gained to all partners (#8). LaVeaux and Christopher discuss how researchers should plan for extended timelines when conducting research among tribal communities.<sup>34</sup> An IRB application was submitted spring 2013 and approval granted eight months later. During these eight months, significant school-based changes occurred on the playground (e.g., playground equipment installation), in the school day structure (e.g., recess periods decreased to one per day), and in the recess grade groupings (e.g., changed to third through sixth grades). These changes had a major impact on the intervention design, yet remained unknown to the research team as there was little communication with the school administration during the IRB process. The proposed intervention was based on no playground equipment and more frequent recess periods. Also, IRB approval was on previous recess grade groupings (fourth through sixth grade children), which were no longer applicable. Similar experiences with structural school day changes are reported in other studies.<sup>3,11</sup>

The unanticipated changes impacted the research team's ability to implement the proposed intervention. In response, the intervention was revised to accommodate changes. The playground equipment served as a control zone and IRB amended to include third graders. The new recess schedule was an uncontrollable change.

The lesson learned is that school-based research takes extended time, and may include changes to the school day structure. It is recommended to maintain regular communication with school partners during the IRB process to stay apprised of changes. This will allow for IRB amendments as needed. These processes relate to the CBPR principle of involving a cyclical and iterative process (#6). Although other school-based studies describe challenges, <sup>2,9,12,37</sup> none discuss how changes to playground and school day schedule can impact study design, and none provide an example for how to respond to these challenges.

### **Design Sustainable Intervention Components**

Permanent game areas—four-square, nine-square, and hop-scotch lines—and basketball court boundaries were painted on the playground such that children were able to use them beyond the study.<sup>40</sup> The remaining paint was donated to the school. Sporting equipment

(e.g., football, soccer ball) was provided during the intervention, and donated to the school. The painted lines and donated equipment represent environmental factors that contribute to health, relating to the CBPR principle of addressing health from an ecological perspective (#7). Children were able to use these resources long after the intervention concluded. In addition, the paint made it possible for the school to repaint lines when needed. Collectively, the lesson learned is to employ simple strategies to sustain the intervention once the research has concluded.<sup>36</sup>

Academic-community partnerships also relate to sustainability. It was discussed during initial meetings that the partnership may not continue beyond the project. Despite study conclusion, academic co-investigators continue to work with the tribe and publish work together.<sup>41-45</sup> In addition, the doctoral student completed degree requirements, resides in the tribal community, and conducts CBPR research with tribal communities in Montana and Arizona.

### **Collaborative Dissemination Practices Build Trust and Capacity**

The study protocol required tribal approval for data dissemination. Accordingly, all manuscripts were sent to the THD and tribal IRB for approval prior to publication. Keeping with the CBPR principle to disseminate findings to all partners (#8), the research team met with the THD director to discuss each manuscript and dissemination plans. This included school board, THD, and tribal council presentations. In addition, aggregate study data was provided to the school board. These actions fostered trust between the research team and the tribe, and align with the CBPR principle of conducting research with respect and mutual benefit to the all partners (#4).

The lesson learned is that community-academic relationships are strengthened by following tribally mandated protocol for dissemination. Furthermore, this process relates to the CBPR principle that builds trust and capacity for future research partnerships (#2). Finally, the process of developing, implementing, and evaluating the intervention relates to the CBPR principle of conducting a cyclical and iterative process for both the research team and tribal community (#6).

### **Not all CBPR Principles Will Be Used in Each Project**

Perhaps the most impactful lesson learned is that navigating CBPR is unique to each study. Although the eight CBPR principles serve as a guide, they do not apply in a uniform manner to every study. Wallerstein et al.<sup>46</sup> discuss the importance of not adopting all principles “as-is” and imposing them on partnerships where they do not fit. Each study and population is unique and CBPR principles should be adopted where appropriate. For instance, time and budget constraints prohibited community member participation during phases of data analysis. Although only one community member was a coauthor on publications, co-authorship with multiple community members would have been ideal. Nonetheless, three tribally enrolled undergraduate community health science students participated in data collection and analysis, two of whom presented an academic poster describing formative results.



## CONCLUSIONS

This article describes the CBPR approach used for—and lessons learned from—an intervention to increase school day child PA in a tribal community on an AI reservation. The mixed-methods approach was challenging and time-consuming, with immense time spent in the formative phase developing relationships and obtaining community and IRB approvals.<sup>36</sup> However, the relationships established built trust as the project proceeded through each step of the research process in a transparent and respectful manner.

The lessons learned reinforce the importance of tribal partnerships in every step of the process. Ample time must be scheduled to maintain relationships amidst unexpected changes—such as leadership turnover—during and beyond the formative phase. Disseminating results to the community throughout the process may identify needs that can be addressed by community leaders, which strengthens community capacity. Researchers may encounter an uncharted path when navigating both university and tribal IRBs. Yet, communication of IRB authority can negotiate a successful course forward. To promote lasting impact, the research should include sustainable components where possible. Finally, conducting school-based research with tribal communities takes time. The time spent developing relationships and obtaining appropriate approvals contributes to establishing trust and ensuring the work will benefit the community.

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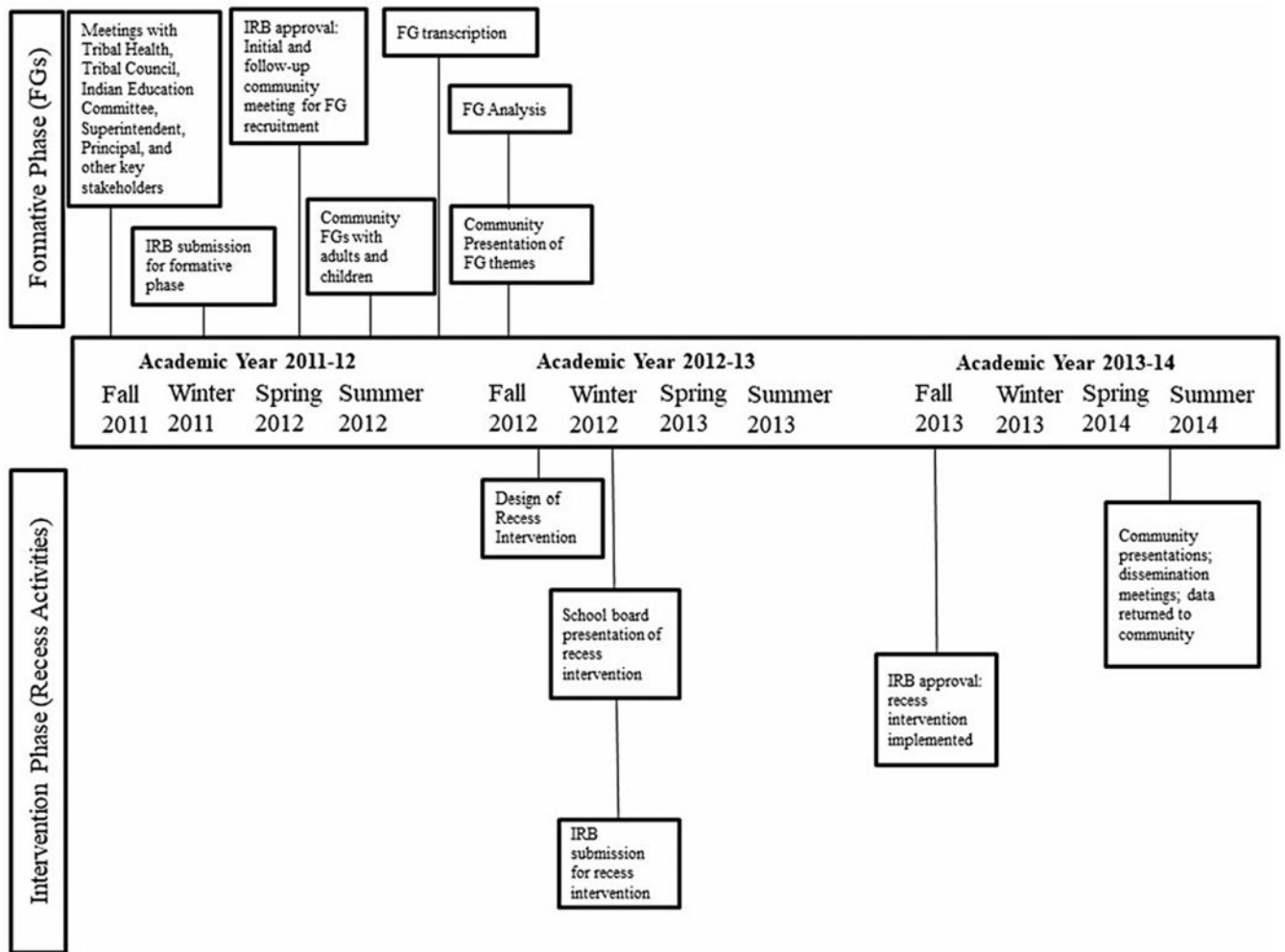
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**Figure 1.** Study timeline of formative and intervention phases of the project

**Table 1.**CBPR Principles Developed by Israel et al.<sup>33</sup>

(#1) Recognizes community as a unit of identity
(#2) Builds on strengths and resources within the community
(#3) Facilitates collaborative partnerships in all phases of the research
(#4) Integrates knowledge and action for mutual benefit of all partners
(#5) Promotes a co-learning and empowering process that attends to social inequalities
(#6) Involves a cyclical and iterative process
(#7) Addresses health from both positive and ecological perspectives
(#8) Disseminates findings and knowledge gained to all partners

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