CAIR Center for American Indian Resilience

Toolkit for Community-engaged Wellness Mapping

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Introduction

Community-engaged projects have become one of the preferred ways to build capacity, conduct research, and promote social change in a variety of fields. Our project, *Health Resilience among American Indians in Arizona*, began as a research initiative to identify resilience strategies used by community members in their search for a healthier life. Previous research showed the need for improving patient-provider communication in relation to wellness, health, and strategies for a healthy lifestyle; therefore, an in-depth look at patient-provider communication is also a part of the research objectives.

Our research team included community members, academic personnel, and students. We developed a Wellness Mapping toolkit to engage team members in a process of data collection and analysis in a mixed-methods project design. We used the Wellness Mapping toolkit in a variety of community settings, and with groups of people of different ages, educational backgrounds, and languages.

The use of this Wellness Mapping toolkit helped team members with varying levels of training to collaborate in a process of research and analysis. Through the use of the toolkit the team achieved data collection and provided an opportunity for capacity building among members. The authors find these tools flexible, easy to use, and easy to adapt to several endeavors, and hope the tools can be of use for other community initiatives and projects.

Approach and Methods

A Community-based Participatory Research (CBPR) approach has been the cornerstone of multiple health related projects. [1-3] The principles of CBPR have helped shape projects where community members actively engage in research and social change, bringing their knowledge as a valuable resource to address health disparities and community-identified problems. Rapid Assessment, Response and Evaluation (RARE) [4-7] is a community-engaged approach to collecting and analyzing data in partnership with researchers and community members that is similar to CBPR, however designed to collect data more quickly and with more defined roles for trained research engagement with community members. Researchers developed and continue to use RARE to conduct intense assessment among different groups of people who may be suffering from specific health conditions, or in communities seeking general assessments about needs and assets. The development of RARE began with the need to identify practical recommendations for impacting the spread of HIV in urban centers across the United States[4,6,7] and was later expanded internationally as I-RARE.[8-9]

The RARE approach incorporates knowledgeable community members as researchers. For our project we are using the term "community researchers" to designate community members who work as non-academic co-researchers with the academic team. Community researchers receive training in RARE methodology and actively participate in data collection, analysis, and discussions about the project direction and results.

RARE provides a toolkit from which community researchers can choose and adapt the strategies that they will use for data collection and preliminary analysis. Data collection methods in the toolkit include interviews, social mapping, focus groups, and street intercept surveys. Advantages of RARE include the ability to support a shorter, intensive, data collection period by incorporating the knowledge and social networks of community researchers, as well as maintaining a community perspective in the analysis portion of the project.

The *Health Resilience among American Indians in Arizona* project design included the principles of collaborative research with community members and local organizations and a RARE approach to the data collection process. The project also took a resiliency approach, meaning it was geared towards identifying positive behaviors and strategies that people use to achieve and maintain health and wellness. Resilience studies are frequently framed in terms of risk and protective factors for American Indian populations;[10-12] however, more recent literature highlights the power of resilience strategies and their role in health and wellness.[13, 14] In line with these most recent approaches to resilience, the Center for American Indian Resilience-CAIR defines resilience as:

> The *ability to move forward like a willow with renewed energy, with a positive outlook with attainable goals to achieve one's dreams, and overcome negative life experiences from current and past political and historical events, with the goal to reduce health disparities among American Indians*. [15]

Relevance of Toolkit

In our experience, the characteristics of this toolkit make it especially successful in CBPR-RARE project structures. The authors encourage the use of the toolkit taking into consideration a locally appropriate research design and implementation. One option for the use of this toolkit is to present the tools to a group of collaborators and have them complete the mapping activity. Once the collaborators complete the activity, the group may want to discuss the usefulness of the tool for particular research questions, any modifications the group would like to make, and strategies for obtaining approval from an Institutional Review Board and recruiting and working with participants in the area of study. There are several benefits to using this toolkit within a larger mixed-methods approach. The benefits of this Wellness Mapping toolkit include:

- **Time** - A wellness mapping activity takes less time one-on-one than a full semi-structured interview, and may be used in groups. This shorter timeframe allows researchers to potentially conduct a greater number of wellness mapping activities than they might with full 1-2 hour interviews. The mapping activity is also easy to integrate with other research methods; for example, not only did we use the activity by itself but also in combination with interviews and surveys/questionnaires about wellness.

- **Elicitation** – The use of wellness maps allow for elicitation of unanticipated data. The question "tell me about what you drew here and why it is red," may be more effective for some participants than more direct interview or survey questions. Even our group of researchers indicated surprise at the information that they presented when participating in the activity for the first time. The tool also allows researchers to connect with people who may not enjoy or feel comfortable talking about their experience and find drawing to be an easier and more participant-led activity than a focus group or interview. Since the wellness mapping is framed in an open way, participants who do not want to draw can elaborate other types or responses such as lists of words categorized by color.

- **Participation and Recruitment** - Requests for a 30-minute mapping activity may also result in more participation from a larger number of people. Less time involvement may also be a consideration in the distribution of incentives in projects with limited budgets. This tool also works well with people who may not share a common language or language fluency, or children who might enjoy drawing and sharing information more than talking through a focus group or interview. As mentioned before, we have used this tool in a variety of settings (community meetings, social events, interviews) proving its adaptability and efficiency. Participants who used this tool were from diverse ethnic and cultural origins, ages, and genders.

- **Data collection and Analysis** – This tool allows new researchers to conduct research with less training than might be involved for other research methods. While ethics and research methods are important for the use of this (and any) data collection tool or toolkit, this is easily administered with minimum training time. Analysis is also exciting for research teams who have the ability to lay out all of the maps and look at visual patterns that they see occurring in the maps as an entrée into a discussion of patterns and data analysis.

- **Research Artifacts** – Finally, this activity produces interesting visual objects for participants as well as researchers. With permission from participants, you may use the maps as posters, in reports, or even as symbols of a project in ways that help to communicate project goals and results.

Research Ethics

We propose the use of this tool in conjunction with ethics training and approval by an Institutional Review Board (IRB). As is the case with all social science research, researchers will be collecting data that may have deeply personal meanings attached. It is crucial for all researchers to have thoughtful training on how to handle wellness mapping when participants experience distress. Participants in our research, for example, remembered abuse and violence, and discussed places that caused stress or anxiety. In addition to the ability to work with participants to make sure they feel safe during and after the interview, researchers must also have the training necessary to hold all participant data confidential. In a case where someone reveals social data, for instance, a researcher must know the importance of confidentiality. The same is true for any information such as names or personal addresses, or health status that a participant may reveal. In one interview, a well-known neighborhood resident revealed his trips to meet with a parole officer and an oncology center where he had to go on a regular basis. These data are important and must be confidential in order to protect the identities of all participants.

We used this training in the context of a community-engaged research project with several IRB approvals: one from the university where the academic researchers are housed, one from the local hospital's IRB, and two from Native American and tribal boards. These approvals gave our participants and researchers confidence about the rigorous nature of research procedures and data confidentiality.

Training

This set of tools is intended for use with an engaged team including at least one team member who is experienced in data collection, and most importantly, data analysis in the area of study. The toolkit contains instruments for team analysis so that researchers at all levels might use the tools to engage in the process of analyzing data in partnership with other researchers who can guide and explain data collection and analysis. Training for the use of these tools may include collaboration and discussion of overall project goals and the development of research questions, ethics, methods of data elicitation, and an introduction to analysis. These processes of collaboration and discussion were not limited to the initial phases of the project, but were a consistent part of the data collection stage allowing researchers to adjust and improve the tools as they were tested and used in the field.

We used iterative theme analysis; however, each team may choose a different strategy for analyzing your data based once again on the goals of a specific local project and the other methods you may be using in conjunction with wellness maps.

Description of Analysis

The RARE process that we used for this project was applied not only for the data collection phase of the project but also for the initial analysis phase of the findings. To facilitate the process of analyzing large amounts of quantitative data, we established a 3-level structure for the team meetings. The identified analysis levels are:

- **Individual Analysis** –At the first level of analysis, community researchers looked at the information and themes that a particular individual mentioned during his/her interview and recorded them as a key point list.

- **Researcher Analysis** – In this level of analysis, community researchers looked at all the interviews they conducted to find patterns and recurrences in the information provided by participants and observed by them. Since most of the interviews were done in teams of two, it creates an opportunity for community researchers to be aware of the different perspectives each brings to the project, and to receive feedback from each other and other team members. The template for this level of analysis was structured for our weekly meetings with a space for the community researcher to include all the key point lists from the week.

- **Team Analysis -** at our weekly meetings, each team member used their researcher analysis template (weekly list of key points) and shared their findings with the group. The group was able then to compare and summarize themes and key points expressed by the participants.

The use of three different templates allowed researchers to identify the information that was asked for on each analysis stage, and to separate the process into smaller, more manageable sections. One downside of these tools is that they require a learning curve during the first weeks of analysis, but once that learning process has been done the process becomes easier. These tools also require a person in charge of following up and clarifying any questions that might arise during the learning stage of the process.

Presentation of Toolkit Components

1. Wellness Mapping tool

Proposed Protocol Options for Wellness Mapping

Instructions
Collaborate Familiarize yourself and your team with toolkit. Choose a team of community researchers to review the existing tools and decide the usefulness of the tool in relation to the goals of the project, and if and how they would like to modify the associated tools and any foci or research questions for the community. The team may want to discuss procedural questions such as: • Who will the researchers engage in the process (sampling strategy)? • How many wellness maps will the team aim to obtain? • How will researchers recruit participants? • Will the team use incentives? What is an appropriate incentive for this group? • Where will mapping activities take place? In public? In private? How will the team ensure safety of all researchers and participants? • What types of ethical questions may arise during the use of the toolkit and what Institutional Review Board approvals will the team need to complete? • How will researchers record participant responses? What will happen to maps once they are complete? Where will they be stored? How will the team collect and analyze them as a set? • Who will hold responsibility of collecting all data including any recordings, notes, maps, consent forms, notes, and other research objects and organizing and ensuring confidentiality of all associated files, photos, maps, and everything included in the toolkit? • Where will all data be stored, and for how long? • If part of the research project, how will the analysis be disseminated to participants? ***Pilot test*** Once the team develops a well-organized plan for implementation of the toolkit, a best practice approach is to run a pilot test of the tools. Each researcher uses the tool with other members of the team, or with an outside research participant, in order to suggest possible revisions and ideas for improvement. Following the pilot test of the toolkit, the team meets to discuss its usefulness, and decide on changes to the process before beginning full-scale data collection. ***Recruit*** Recruitment of research participants is the next step. After researchers agree on how to use the toolkit they will recruit possible participants that match the sampling strategy. Researchers can either conduct the mapping activity with participants in a public location or at a meeting or event, or choose another time and place to schedule the mapping activity. Each participant will need a piece of paper and drawing materials to construct a map. Throughout *Health Resilience among American Indians in Arizona* the research team noted that offering multiple types of materials provided participants with options for creative expression through color or texture. ***Build rapport*** One of the most important aspects of successfully completing mapping activities is the ability to quickly build rapport and put the participant at ease by saying things like "you don't have to be an artist," and "anything you draw is fine." Once the mapping activity and mini-interview are complete the researcher thanks the participant, provides incentives (if planning to use them), and collects or photographs the map. As quickly as possible after the activity the researcher uses the analysis templates to write notes and key points on the content of the activity, including any observations that were not recorded, and identifies patterns based on a growing knowledge of the project goals.

Explanation of the Activity
Script: We would like for you to draw a map of all the things in your environment that you associate with wellness. For this map, you do not have to be an artist. If you want to draw symbols and stick figures that is perfectly fine. This map may or may not include where you live, where you work, and places that you go on a regular basis, either by yourself or with your family. This is not a geographical map that is drawn to scale. It is a map about how you see the world around you. Your map can include symbols, pictures, words, or anything you think of when you think of wellness in your environment. You may want to color code or use symbols to indicate different stressors/ or to group different components to wellness. Once we are finished with the map we will discuss what you drew. During the discussion I may take notes or ask questions to remind myself of what was said and to ensure my accurate understanding of your description. Do you have any questions or concerns before we begin this activity? Note: Someone may ask you to define wellness- if this happens, you may choose to turn the question back to them and say, "how do you define wellness" (and try to make this a group discussion by emphasizing that there is no wrong answer and we are really interested in knowing more about the participants' definitions of wellness).

Discussion (after completion of maps)	
INDIVIDUAL SETTING	**GROUP SETTING**
The setting of this description can be more of a conversation with the participant describing their map and the researcher asking questions (i.e. the participant draws a picture of a park and says that they go running there- the researcher can then ask, which park is that, how often do you go running there, why do you go running there, why do you associate that with wellness, etc.). The researcher will take notes during this portion of the conversation	To protect confidentiality the research team may identify a data collection system for pairing the map with the audio recorded description and the researcher notes. For instance; each participant could be given a number that they write on their map and then they introduce their map as map number ___ (this way the map does not have their name on it). The researcher may choose to facilitate a group conversation or focus group allowing other participants to ask questions about each others maps or identify similarities (i.e. "look at all the maps that have mountains on them. How many of us did that?' or 'really? You put the library on there? I never go there. Does anyone else?') This allows the researcher[s] to obtain the social data that occurs in a group setting. Also- though the researcher may ask direct questions from the participant (as was described in the Individual setting description) the researcher may not want to be as proactive in probing the participants in a group setting in order to allow for others in the group to lead the direction of the conversation.

Analysis

Researchers will want to provide legible or typed notes for each interaction that will be paired with recordings and notes.

There are a couple options for analysis. The drawings and descriptions can be analyzed separately and then analyzed together (this may allow for further layers to the data to be discovered). It may be easier to analyze the drawings in conjunction with their descriptions (for the purposes of understanding the drawings).

Example of researcher description from a group mapping activity:

> *The participant spent a lot of time talking about how her family is a strong support system, but in her map she drew an image of the gym and the grocery store. Perhaps during the activity she initially thought about physical activity and nutrition attributing to wellness, but after hearing from other participants and their definitions of wellness, they decided to interpret wellness in a broader sense.*

It is also be helpful to examine overall commonalities between participant's maps. For example, "a lot of participants drew items relating to spiritual wellness, but few drew images showing a connection between relationships and wellness," OR, "6 of the 9 participants drew images of this one gym, but few participants actually used that gym because it was too expensive and had limited hours."

2. Interview & mapping log (level 1 of analysis)

Interview & Mapping Log

<table>
<tr><th colspan="2">Activity Log</th></tr>
<tr><td>Location:</td><td>Date:

Start time:

End time:</td></tr>
<tr><td>Interviewer name:

Recorder/note taker name:

Participant code:</td><td rowspan="2">Description of setting and participant:</td></tr>
<tr><td>Other information:</td></tr>
</table>

Post-Interview Narrative & Memos

Narrative
Please use the space provided (and additional space when necessary) to write a detailed description of the interview. Include all relevant details. Did the participant seem particularly interested in one part of the activity over another? Did you notice any discomfort about any topics? What can you record about the interaction that you might not see when you look only at the map?
Narrative:

Memos & Themes

Please use the space provided to write down **memos** after conducting an interview.

Memos are a list of key ideas or observations that the researcher identified during or after the interview. *Example: "Participant drew family members in green and seemed to return to family as an important part of her wellness over and over again."*

Memo:

-
-
-
-
-
-
-

Use the space below to write down themes or patterns you identify between this mapping activity and others you have conducted or discussed with your team members. Do you see anything in this map and/or interview data that reminds you of others? Do you see or did you hear anything different in this activity and interview from others? *Example: "I have noticed that 4 or 5 people listed libraries as a stressor. May want to count how many people have listed libraries and discuss with team."*

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