# **BMJ Open** Best practices for community-engaged participatory research with Pacific Islander communities in the USA and **USAPI:** protocol for a scoping review

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#### ABSTRACT

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Introduction Community-based participatory research is a partnership approach to research that seeks to equally involve community members, organisational representatives and academic partners throughout the research process in a coequal and mutually beneficial partnership. To date, no published article has synthesised the best practices for community-based participatory research practices with Pacific Islanders.

Methods and analysis The reviewers will examine studies' titles, abstracts and full text, comparing eligibility to address discrepancies. For each eligible study, data extraction will be executed by two reviewers and one confirmation coder, comparing extracted data to address any discrepancies. Eligible data will be synthesised and reported in a narrative review assessing coverage and gaps in existing literature related to community-based participatory research with Pacific Islanders.

Discussion and dissemination The purpose of this review is to identify best practices used when conducting community-based participatory research with Pacific Islanders; it will also extrapolate where the gaps are in the existing literature. This will be the first scoping review on community-based participatory research with Pacific Islanders. To facilitate dissemination, the results of this scoping review will be submitted for publication to a peer-reviewed journal, presented at conferences and shared with community-based participatory research stakeholders.

# INTRODUCTION

Community-based participatory research (CBPR) is an approach to research that seeks to equally involve community members, organisational representatives and academic partners throughout the research process in a coequal and mutually beneficial partnership.<sup>1-5</sup> CBPR is not a specific research method but rather a realignment to research that seeks to foster an environment of shared power. This approach is in contrast to traditional research ontological positions wherein the academics are the experts conducting research with little input from the community

# Strengths and limitations of this study

- ▶ This is the first scoping review to address the literature on community-based participatory research with Pacific Islanders.
- The review will provide a synthesis of existing studies, it will be useful to community-based participatory partnerships with Pacific Islanders, and other collectivist cultures.
- This scoping review is focused on assessment of the coverage and gaps in the existing literature, so quality assessment of individual studies will not be a primary emphasis.

being studied. The essential components of CBPR include: equitably including a specific community in all phases of research; building capacity within a community to drive the focus of the research that is of interest to community stakeholders; and implementing research that results in tangible action and directly improves the community's well-being.<sup>5</sup><sup>6</sup> CBPR has demonstrated efficacy in building alliances to conduct research with disenfranchised communities.<sup>1</sup> Engaged research is referred to by other terms including action research, CBPR and patient-centred research; the term CBPR will be used throughout this protocol.

#### BACKGROUND

Pacific Islanders are the second fastest growing population in the USA, and grew 40% between 2000 and 2010.7-9 In addition to the continental USA and Hawaii, many Pacific Islanders reside in the US Affiliated Pacific Islands (USAPI). The USAPI includes three US territories: American Samoa, the Commonwealth of the Northern Mariana Islands and Guam, and three independent countries in free association with the USA: the Federated States of Micronesia, the Republic of the Marshall Islands and the Republic of Palau. Pacific Islanders are under-represented in health research, and much of the available research aggregates data from Pacific Islanders and Asian Americans, obscuring the disparities between and within these two heterogeneous populations.<sup>10-14</sup> While data aggregation has limited the amount of available data, existing research reveals profound health disparities among Pacific Islanders compared with the general US population.<sup>15-39</sup> These disparities include higher rates of diabetes, cardiovascular disease, obesity and cancer.<sup>40–44</sup> While national data about life expectancy are not available for Pacific Islanders due to aggregation,<sup>45-47</sup> individual state and US territory data document life expectancy for Pacific Islanders as 68.3 years,<sup>48</sup> compared with the life expectancies of 78 years for non-Hispanic Whites and 79 years for the total US population.47

Pacific Islanders' health disparities can be attributed to many factors, including a history that has been marked by trauma, exploitation and exclusion. Between 1946 and 1958, the US military detonated 67 fission and thermonuclear devices in the USAPI region, which were equivalent in payload to 7200 Hiroshima-sized bombs.49-52 These nuclear tests caused acute radiation exposure and subsequent illness, and contaminated the soil, ocean and fresh water resources of the USAPI region of the Marshall Islands resulting in food insecurity and serious long-term health effects.<sup>50 52-59</sup> After nuclear testing, the USA began Project 4.1 in which Islanders who were exposed to nuclear fallout were interned in a camp in order to study the effects of radiation on humans.<sup>60–63</sup> The research was conducted without the informed consent of the Pacific Islanders and without translation of the study information into the native language.<sup>52</sup> This historical trauma has contributed to deep apprehension and distrust of western medicine and research.<sup>64–69</sup> Historical trauma perpetuates ethical challenges that must be addressed in order to conduct research with Pacific Islanders.<sup>7071</sup>

One way to address the effects of historical trauma on Pacific Islander communities' perceptions of research is through CBPR.<sup>70 71</sup> CBPR shares power and builds trust between academic researchers and the community.<sup>72 73</sup> There is evidence for the effectiveness of using CBPR to engage minority, immigrant and migrant populations in research to reduce health disparities.<sup>74–79</sup> In addition, there is evidence for the effectiveness of using CBPR to reduce health disparities in populations that have experienced historical trauma.<sup>80</sup> To date, no published article has synthesised the best practices for CBPR practices with Pacific Islanders. This leaves an important gap in the literature as researchers seek to address the profound health disparities in the rapidly growing Pacific Islander population in the USA.

# Table 1Study eligibility criteria

Participant population	CBPR studies conducted with Pacific Islanders in the USA or USAPI of any sex or age. Studies that aggregate Pacific Islander and Asian American data will be excluded. Study conducted with Pacific Islanders outside the USA or USAPI will not be included.
Study type	All types of studies focused on mental and/or physical health
Outcomes	CBPR challenges and best practices
Context	Articles that self-identify as using a CBPR approach (or other engaged research term such as action research or patient-centered research)
Study methods	All types of studies (eg, randomised controlled trials, mixed methods, cross-sectional, descriptive, qualitative, case studies, and so on)

CBPR, community-based participatory research; USAPI, US Affiliated Pacific Islands.

#### **OBJECTIVES**

The aim of this scoping review is to examine the best practices for conducting CBPR with Pacific Islanders. Information from the review can be used to guide CBPR research focused on addressing the health disparities among Pacific Islanders. The review will respond to the following question: What are the effective best practices identified by previous CBPR researchers for conducting community-engaged research with Pacific Islanders in the USA and USAPI? Best practices are defined as the methods identified as most effective (ie, successful) by CBPR researchers across multiple studies as outlined by Israel *et al.*<sup>81</sup>

#### **METHODS**

The scoping review protocol was designed in accordance with the Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols statement.<sup>82,83</sup>

#### **Eligibility criteria**

Studies will be selected according to the following criteria (table 1):

Studies will be limited to research conducted with participants residing in the USA and USAPI. Studies published between January 2000 and December 2017 in peer-reviewed journals will be included in the review. Only those studies that focus solely on Pacific Islanders will be included. Pacific Islander subgroups include (but are not limited to): Chamorro, Chuukese, Maori, Marshallese, Native Hawaiian, Samoan and Tongan. Studies that include Asian Americans aggregated with Pacific Islanders will not be included. For the purposes of establishing study eligibility, *CBPR* will be defined as an

approach to research that seeks to equally involve community stakeholders and academic partners in the research process in a mutually beneficial partnership.<sup>6</sup> Studies that self-identify as CBPR or a related term will be included.

## **Information sources**

The following biomedical databases will be searched for articles meeting the eligibility criteria and focused on English language items with 2000–2017 publication dates. These databases include: MEDLINE (OVID), MEDLINE In Process & Daily Updates (OVID), International Pharmaceutical Abstracts (OVID), Cumulative Index to Nursing and Allied Health Literature-CINAHL Complete (EBSCO), Health Policy Reference Center (EBSCO), PsychINFO (EBSCO), SocINDEX (EBSCO), Science Citation Index, and Social Sciences Citation Index (both via Web of Science). The search of All EBM Reviews (OVID) will include: ACP Journal Club, Cochrane Database of Scoping Reviews, Databases of Abstracts of Reviews of Effects, Cochrane Central Register of Controlled Trials, Cochrane Methodology Register, Health Technology Assessment and the NHS Economic Evaluation Database. The WHO's Global Health Library will also be searched for international items. Three researchers will review references for inclusion.

## Search strategy

The search strategy will be developed by medical librarian coauthor SCS, in consultation with coauthors PAM, BLA, RSP and CRL. Medical Subject Headings (MeSH) will be used and explored where appropriate. To obtain a comprehensive set of results, MeSH terminology will be combined with advanced textword searching techniques including truncation and adjacency searching. MeSH headings chosen to make up the base strategy include: exp Oceanic Ancestory Group/AND Community-Based Participatory Research. MeSH and other controlled vocabulary headings will be combined with extensive strings with synonymous terms for each main concept. Pacific Islander terms include: ('pacific islander' or 'native hawaiian' or Hawaii or 'ni'ihau' or niihau or 'kaua'i' or kauai or 'o'ahu' or oahu or 'moloka'i' or molokai or 'lana'i' or lanai or 'kaho'olawe' or kahoolawe or maui). mp. or ('austral islands' or australasia or 'caroline islands' or carolinian or chamorro or chuuk or chuukese or 'cook islands' or 'easter island' or fiji or fijian or 'futuna island' or guam or guamanian or 'i-kiribati' or kiribati or kosrae or kosraean or 'mariana islander' or 'mariana islands' or 'marshall islands' or marshallese or melanesia or melanesian or micronesia or micronesian or 'new caledonia' or niue or 'ni-vanuatu' or 'pacific islander' or 'pacific islands' or palau or palauan or 'papua new guinea' or 'papua new guinean' or 'phoenix islands' or 'pitcairn islands' or pohnpei or pohnpeian or polynesia or polynesian or 'rapa nui' or saipan or saipanese or 'american samoa' or samoa or samoan). Similar synonymous terminology searching will be combined multiple ways to reach the CBPR concept. Controlled vocabulary headings, search

Table 2   Data to be extracted	
Participant population	<ul> <li>Race/ethnicity</li> <li>Subgroup of Pacific Islanders</li> <li>Geographical location</li> <li>Sex</li> <li>Age group</li> </ul>
Study design	<ul> <li>Randomised controlled trial</li> <li>Case study</li> <li>Others</li> </ul>
Study method(s)	<ul> <li>Qualitative</li> <li>Quantitative</li> <li>Mixed methods</li> <li>Others</li> </ul>
Study setting	<ul> <li>Churches</li> <li>Clinical setting</li> <li>School systems</li> <li>Community setting</li> <li>Others</li> </ul>
Best practices	Best practices related to CBPR design, implementation setting, individuals involved and implementation process (eg, recruitment, data collection, retention, dissemination)
Publication details	<ul> <li>Authors</li> <li>Article title</li> <li>Journal title</li> <li>Year of publication</li> <li>Volume number</li> <li>Issue number</li> <li>Issue numbers</li> <li>Funding source</li> <li>Was a community author identified?</li> </ul>

CBPR, community-based participatory research.

strings and the overall strategy will be adapted as needed for other vendor platforms specific to the database used. These adapted strategies and terms may be requested from the corresponding author (PAM). The search terms and strategy to be used from MEDLINE (via OVID) are presented in online supplementary appendix 1.

#### **Data management**

Search results will be exported, stored and shared among coauthors using Endnote (V.6.0.1) a bibiographic reference management tool. Duplicate records will be removed from search results by using manual oversight to ensure accurate duplicate removal. The final, unique set of records will be uploaded to Rayyan, a free online tool that allows for easy screening of systematic/scoping review results. As necessary, records will be exported to Excel 2013.

#### Study selection process

The title and abstract of manuscripts will be reviewed to determine whether the study meets all the eligibility criteria. If the title and abstract of any manuscript do not provide enough information to confirm eligibility, the full article will be reviewed by two researchers to determine if it meets the inclusion criteria. If it is still unclear if the manuscript is eligible, a third reviewer will review the manuscript and a final decision will be made. In the event that multiple publications of a single eligible study are identified, both publications will be included. However, when tabulating quantitative results care will be taken to avoid double-counting single studies.

#### **Data extraction process**

Data extraction from each eligible study will be performed by two researchers independently. Then, they will compare the results of the extraction process. Discrepancies in extracted data will be discussed and resolved between the researchers; a third reviewer will be consulted if necessary. If data extraction for an eligible study cannot be completed due to inadequate description of the study in an article's full text, researchers will contact the publication's corresponding author via email (up to three attempts) to acquire the missing information. If there are multiple publications of a single eligible study, data will be extracted from the multiple publications. In these cases, extracted data will be evaluated across publications for any inconsistencies. If inconsistencies are identified, researchers will attempt to resolve inconsistencies through discussion or by contacting the publications' corresponding author via email (up to three attempts). Before data extraction begins, researchers will pilot the extraction spreadsheet on a small sample of eligible studies and adjust the extraction spreadsheet or extraction procedures as necessary.

#### Data items

The following data will be extracted from each eligible article (table 2):

Because this scoping review's focus is to assess the coverage and gaps in the literature about CBPR best practices with Pacific Islanders, quality assessment of individual eligible studies will not be a primary focus of the data extraction process.

#### **Data synthesis**

Data synthesis will include producing quantitative summaries of extracted data that include frequencies and percentages for many of the extracted data fields. For the Best Practices Field, the researchers, trained in qualitative methods, will begin by coding each segment of data using an inductive coding process to generate a list of emerging best practices. Then researchers will organise emergent codes into a code book that will be used to code each data segment. This process will help organise the data for focused thematic coding and allow the researchers to create salient summaries of best practices.<sup>84 85</sup> These summaries will be used to present the convergent and divergent themes within the studies. Additionally, these summaries will allow us to identify gaps in the existing literature.

The purpose of this scoping review is to identify best practices used when conducting CBPR with Pacific Islanders; it will also extrapolate where the gaps are in the existing literature. This will be the first scoping review on CBPR with Pacific Islanders. The article will expand the available knowledge on CBPR methods which have shown success in reducing health disparities in African American, Hispanic/Latino and other minority groups.74-80 For this reason, it will be useful to CBPR partnerships with Pacific Islanders who are seeking to address the profound health disparities in the rapidly growing Pacific Islander population. The outcome of this article can serve as a guide for researchers and community members seeking to address health disparities in diverse Pacific Islander communities. For example, those seeking to address a wide variety of health conditions from Hansen's disease to obesity can use the cumulative best practices in the scoping review to guide their CBPR methods including engagement, recruitment, data collection, retention and dissemination.

#### Dissemination

To facilitate dissemination, the results of this scoping review will be submitted for publication to a peer-reviewed journal, presented at conferences and shared with CBPR stakeholders.

**Contributors** PAM, BLA, RSP, CRL, KS and ME designed the protocol, and SCS developed the search strategy in consultation with PAM, BLA and RSP. PAM, BLA and RSP drafted the protocol, and SCS, CRL and KS revised the protocol. All authors approved the current version of the protocol.

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