

Open camera or QR reader and scan code to access this article and other resources online.



REVIEW ARTICLE

Open Access

A Systematic Literature Review of Community-Based Participatory Health Research with Sexual and Gender Minority Communities

JaNelle M. Ricks,^{1,2,*†} Elizabeth K. Arthur,^{2-4,†} Shanna D. Stryker,^{2,5} R. Andrew Yockey,^{2,6} Avery M. Anderson,^{2,4} and Donald Allensworth-Davies^{2,7}

Abstract

Purpose: The objective was to review sexual and gender minority (SGM) health research studies to gain an understanding of how the community-based participatory research (CBPR) framework has been operationalized.

Methods: We used the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines to conduct a review of all SGM health research studies published in the past 10 years that cited a CBPR approach (PROSPERO Registration No. CRD42016036608). CINAHL, PubMed, and PsycINFO databases were systematically searched in October 2020. Dimensions of community involvement (e.g., shared decision-making; flexibility to community needs and priorities) and the strength of evidence for each dimension were rated using guidance from the Agency of Healthcare Research and Quality.

Results: The 48 eligible articles identified reported a range of 0–11 (out of 13) community elements. Seven studies reported zero elements. Qualitative studies ($n=28$; 58.3%) had an average quality score of 2.32 (range: 1.43–2.5). The 15 (31.3%) cross-sectional studies had an average quality score of 2.08 (range: 1.64–2.27).

Conclusion: Adhering to the CBPR framework is challenging. The benefits of striving toward its principles, however, can move us toward transformative and sustainable social change within SGM communities.

Keywords: community-based participatory research; sexual and gender minority; health disparities; quality measurement

¹Health Behavior and Health Promotion, The Ohio State University College of Public Health, Columbus, Ohio, USA.

²Equitas Health Institute Midwest SGM Health Research Consortium, Columbus, Ohio, USA.

³The Ohio State University Comprehensive Cancer, Arthur G. James Cancer Hospital and Richard J. Solove Research Institute, Columbus, Ohio, USA.

⁴The Ohio State University College of Nursing, Columbus, Ohio, USA.

⁵Family and Community Medicine, University of Cincinnati College of Medicine, Cincinnati, Ohio, USA.

⁶Biostatistics and Epidemiology, University of North Texas Health Science Center at Fort Worth, Fort Worth, Texas, USA.

⁷Cleveland State University College of Sciences and Health Professions, Cleveland, Ohio, USA.

[†]The authors are co-first authors.

*Address correspondence to: JaNelle M. Ricks, DrPH, Health Behavior and Health Promotion, The Ohio State University College of Public Health, 1841 Neil Avenue, 356 Cunz Hall, Columbus, OH 43210, USA, E-mail: ricks.13@osu.edu

© JaNelle M. Ricks *et al.*, 2022; Published by Mary Ann Liebert, Inc. This Open Access article is distributed under the terms of the Creative Commons License [CC-BY] (<http://creativecommons.org/licenses/by/4.0>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

Correction added on October 7, 2022 after first online publication of February 1, 2022: Co-authorship detail has been included as a footnote.



Introduction

Community-based participatory research (CBPR) is a framework built upon equitable collaboration among scientific researchers, community members, and other stakeholders to improve community health, reduce health disparities, and improve health equity.^{1,2} This adaptive approach engages the community, recognizes and leverages the diverse strengths and contributions of all research partners, and is action oriented in that it seeks not only to understand problems but also to propose cocreated solutions. CBPR principles include the following: colearning between academic and community partners; capacity building and empowerment; mutually beneficial knowledge and findings; bidirectional leadership and decision-making; and long-term commitment.^{3,4}

CBPR shifts the traditional research paradigm which focuses on a specific set of research methods or techniques, largely developed in academic settings, by prioritizing the relationship between academic and community-based research partners and the creation of positive, transformative, and sustainable social change within communities. This represents a systematic effort to incorporate community participation, decision-making, and practices into the research practice.⁵ Actively integrating community members during all phases of the research project helps to ensure that the methods used and data collected are culturally grounded and reflect the lived experiences of the population.^{6,7} Community integration within research teams also has the potential to ensure that health research is acceptable and directly relevant to target communities, potentially improving the rigor of these research efforts overall.

CBPR has been used to examine a variety of health topics such as mental health, food insecurity, diabetes, homelessness, and HIV. It has also been used to assess community characteristics which are key to partnership sustainability, such as capacity, readiness, social capital, and empowerment.⁸ It can be adapted for diverse community collaborations and may be particularly valuable for work with vulnerable and historically underserved communities.^{9–11}

Sexual and gender minority (SGM) is an inclusive term used to refer to a diverse array of people who are gay, lesbian, bisexual, transgender, queer (LGBTQ), gender non-binary or non-conforming, two-spirit, asexual, pansexual, intersex, and other sexual orientation and gender identities (SOGIs). National surveys estimate that ~4–7% of the United States population (or 11 million people, roughly equivalent to the popula-

tion of Ohio) are SGM but are likely underestimates given the failure of survey efforts such as the U.S. Census or American Community Survey to robustly collect this information.^{12,13}

Due to discrimination and social marginalization, SGM people are at risk for poor health behaviors and health outcomes.^{14,15} Compared to their cisgender and heterosexual counterparts, SGM people experience higher rates of HIV infection and other sexually transmitted infections, smoking, drug and alcohol use, and mental health problems.¹⁴ There is evidence that sexual minority women have higher odds of risk factors for hypertension, diabetes, and breast cancer.¹⁴ Transgender adults may have higher risk factors for cardiovascular disease and myocardial infarction.¹⁴ However, due to lack of data collection regarding sexual orientation and gender, the full extent of health disparities experienced by SGM people is not known.¹⁴

Health disparities in SGM people are not caused by their gender or sexuality, but by the discrimination, minority stress, and sociopolitical barriers to optimal health that lead to exposures and behaviors known to contribute to disease and disability.^{16,17} For example, SGM people face barriers to accessing basic health care across the life span, and many experience discrimination or refusal of service when seeking health care.¹⁸ SGM people are also more likely than cisgender, heterosexual people to face employment discrimination and lack health insurance.¹⁸ Even when care is accessed, health care providers are often underprepared to provide affirming health care to SGM people.^{19,20}

SGM communities are heterogeneous, and intersectionality must be considered. SGM individuals differ markedly by not only SOGIs but also in life experiences by age cohort, racial/ethnic group, socioeconomic strata, disability/ability, and immigration status. Integrating intersectionality into health disparity research emphasizes the need to consider this diversity in research, health care, and policy given its influence on an individual's health risks, screening behaviors, and treatment experiences. Intersectionality, a feminist sociological theory, considers the intersection of marginalized or minoritized identities²¹ and how multiple oppressions coexist and interact on various and often simultaneous levels. Intersectional disparities among SGM have also been documented by older age,²² lower socioeconomic status,²³ and immigrant status,²⁴ among others.

SGM communities have historical contexts for community-engaged research. ACT UP (AIDS Coalition



to Unleash Power) was formed in response to social neglect, government negligence, and complacency of the medical establishment during the 1980s.²⁵ ACT UP has advocated for sustained investment in HIV/acquired immune deficiency syndrome (AIDS) treatment and related coinfection research, equitable access to HIV/AIDS prevention and care, and tackling structural drivers (e.g., stigma, discrimination, and poverty) of the HIV/AIDS epidemic.

To make meaningful, impactful progress in SGM health equity, researchers must understand the influence of social determinants on SGM health, as well as the priorities and behaviors of this community, from their perspective. CBPR is well-positioned to more equitably include SGM communities in the pursuit of transformational research outcomes.^{1,2,26} CBPR also has the potential to address noted gaps in SGM health research topic diversification. Although efforts have been made to establish a more comprehensive national SGM research agenda, HIV remains disproportionately prioritized, leaving gaps in other areas such as chronic disease and comorbidity, aging, methods and measurement, and social determinants of health (SDOH).^{27,28}

It has been beneficial in the development of tailored assessment tools for specific populations^{29,30}; assessment of a wide range of chronic health conditions^{31–33}; and addressing the social determinants impacting the health of minoritized communities.^{34–37}

Although the incorporation of CBPR methodology into SGM health research likely has profound benefits, CBPR practitioners face a number of challenges which threaten to limit full implementation of CBPR principles. For example, uncurtailed community-academic partner power differentials, conflicting visions about the work, and limited structural support from funders and academic institutions may lead to minimal community engagement.^{2,38,39} To effectively utilize CBPR to produce findings, knowledge, and outcomes with maximum benefit to SGM people, it is particularly important to characterize community involvement in the research process.

This systematic literature review contributes to the knowledge base by identifying gaps in implementation that limit SGM community members from becoming full partners, contributing their unique knowledge and experiences while also shielding their interests. We present the results of a review of peer-reviewed SGM health studies published over the past 10 years, which describe a CBPR or community-engaged approach, to gain a clear understanding of how CBPR has been operationalized in SGM communities across the United States.

Materials and Methods

This systematic literature review was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses⁴⁰ and has been registered with PROSPERO (Registration No. CRD42016036608), an international database of prospectively registered systematic reviews.⁴¹ Articles were included in the review if they described original SGM health research studies conducted in the United States with mention of CBPR or community-engaged methods and were published between January 2010 and October 2020. “Health research” was categorized broadly, allowing for “health adjacent” topics such as SDOH. Editorials, systematic review articles, meta-analyses, case studies, and methodological articles were excluded.

We searched article titles and abstracts in the CINAHL, PubMed, and PsycINFO databases using keyword combinations specific to CBPR and SGM health research (Supplementary Appendix SA1). The date of the last search was October 12, 2020. Article screening, extraction, and assessment of CBPR criteria were conducted using Covidence[®], a web-based software for management of systematic literature reviews.⁴²

Each of the articles included in the final review was independently assessed by two members of our research team with the reviewers meeting to discuss and reach consensus on discrepant items. We also met as a research team to ensure that data extraction elements and quality criteria were understood and applied consistently during the review process. Data extraction and assessment of CBPR criteria were conducted using the data elements recommended by Viswanathan et al. in their report on assessing CBPR evidence for the Agency of Healthcare Research and Quality (AHRQ) (Supplementary Appendix SA2).⁴³ Assessment of SGM community involvement comprised eight CBPR elements: (1) shared decision-making; (2) community participation barrier removed; (3) socioeconomic determinants of health addressed; (4) flexibility to community needs and priorities; (5) capacity building; (6) findings disseminated to participants; (7) findings applied to health-related intervention or policy change; and (8) intervention sustainability.⁴³

A quality assessment was also conducted to classify each article as good, fair, or poor quality (Supplementary Appendix SA3).⁴³ Quality of each element was rated on a scale of 1–3. One indicated that the article provided insufficient information or that element was poorly captured. A score of three represented the highest quality. A final score (range: 1–3) was calculated by



averaging the scores of all relevant quality elements. Scores were assigned based on what was described in the article and, thus, may under represent elements included but not described in the study design.

The general SGM community was not engaged in the design or conduct of this systematic review. Insofar as the intended audience was SGM health researchers, our author panel comprised members of the Equitas Health Institute Midwest Health Research Consortium, who are all SGM health researchers.

Reflexivity statement

The authors of this article include gender diverse (cis-gender, transgender, and/or non-binary) and sexuality diverse (queer, gay, and straight) researchers who are nurses, a physician, and public health experts in SGM health.

Results

Overview

Forty-eight studies^{44–91} were identified for inclusion in this review, as outlined in Figure 1. A search of the da-

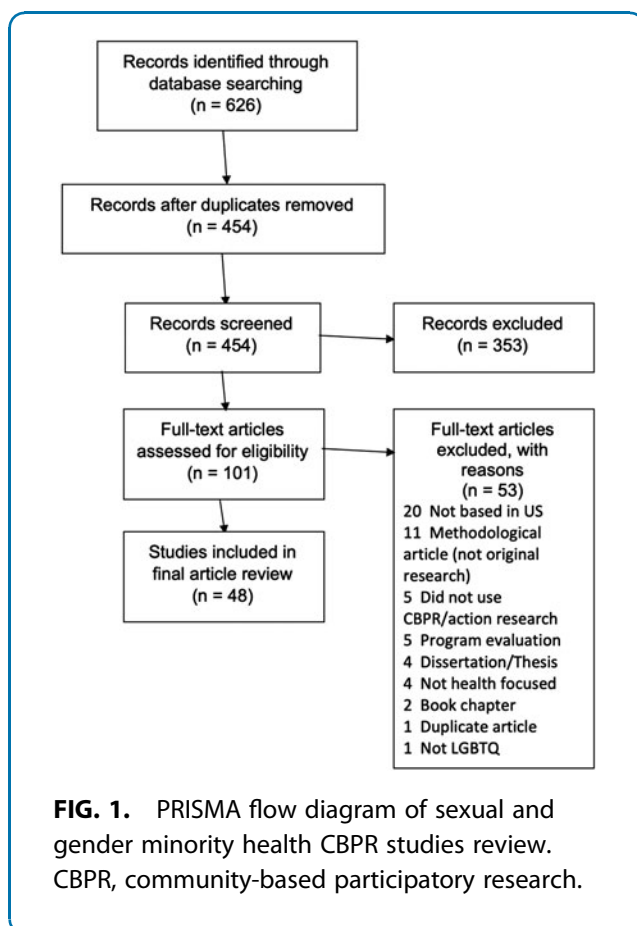


FIG. 1. PRISMA flow diagram of sexual and gender minority health CBPR studies review. CBPR, community-based participatory research.

tabases revealed 454 nonduplicated records, 353 of which were irrelevant based on a review of the titles and abstracts. Of the remaining 101 relevant records, 20 described studies done outside of the United States, 11 were methodological articles which did not share the results of original research, 5 did not use CBPR/action research approaches, 5 described program evaluation only, 4 were dissertations, 4 were related to topics other than health (e.g., education), 2 were book chapters, 1 was a duplicate article not identified on initial screening, and 1 was unrelated to health. As seen in Table 1, there has been a steady increase in the number of articles published on this topic.

Study design

The included studies are described in Table 2. Most of the studies were qualitative (28; 58.3%) or cross-sectional (15; 31.3%). Two reported the results of randomized controlled trials (RCTs), and another described a secondary review of survey data obtained during one of the aforementioned RCTs. All three of the articles sharing results from RCTs were done by the same CBPR partnership in North Carolina.

Table 1. Characteristics of Included Sexual and Gender Minority Health Community-Based Participatory Research Studies (n = 48)

Characteristic	Number of studies (%)
Year of publication	
2010–2011	7 (14.6)
2012–2013	4 (8.3)
2014–2015	10 (20.8)
2016–2017	7 (14.6)
2018–2019	11 (22.9)
2020 ^a	9 (18.8)
Primary topic area	
HIV/AIDS	14 (29.2)
Transgender health	13 (27.1)
Health care access	8 (19.7)
Mental health	7 (14.6)
Youth services	6 (12.5)
Sexual health	5 (10.4)
Substance use	5 (10.4)
Older adult services	4 (8.3)
Physical health	4 (8.3)
Number of funding sources	
None listed	14 (29.2)
1	20 (41.7)
2	8 (16.7)
3 or more	6 (12.5)
Types of funding sources	
Federal	25 (52.1)
State	3 (6.3)
University	20 (41.7)
Private foundations or sources	8 (16.7)

^aLiterature search conducted in October 2020. AIDS, acquired immune deficiency syndrome.



Table 2. Summary of Included Sexual and Gender Minority Health Community-Based Participatory Research Studies by Number of Community Involvement Elements (n = 48)

Abbreviated citation	Sample							No. of community involvement elements (0–13)	Average quality score (0–3)	
	Study design	Primary topic area	Sample description	Inclusion		Age range	Total, N			Study setting
				Bisexual	TGN					
Perone et al. ⁶⁶	Qualitative	Older adult services	Nine participants (45%) were lesbian, 5 (25%) gay, 4 (20%) bisexual, and 1 (5%) queer. Eight participants (38.1%) were people of color, 5 (23.8%) specifically African American or Black.	Y ^a	Y ^a	19–78	21	A large Mid-western city, including four rural and urban counties	11	1.69
Rhodes et al. ⁷²	Cross-sectional	HIV/AIDS	71.2% were gay, 3% heterosexual or straight, and 25.8% bisexual. 56.4% were White, 37.6% Black or African American, 1% were Alaskan native/American Indian, 0.5% Asian. 8.6% reported being HIV-positive, and 14.8% reported never having been tested for HIV.	Y	N	18–61	210	Northwest North Carolina	10	1.93
Smith et al. ⁸¹	Qualitative	Mental health Transgender health	Transgender adults; male (30%), female (50%), non-binary (20%), two spirit (6.7%); 76.6% Caucasian, Latinx/Hispanic (6.6%), Native American (13.3%), Pacific Islander (3.3%)	NR	Y	18–67	30	Rural Montana	9	2.05
Stewart et al. ⁸³	Qualitative	Transgender health	Participants were attendees of trans/non-binary health summits or recruited online. Gender diverse participants (n = 96) were men and/or trans men (31%); women and/or trans women (36%); or a gender included under non-binary (32%). Forty-six percent were bisexual/pansexual/queer and 20% heterosexual. Twenty percent were non-White and 8% were of Hispanic, Latinx, or Spanish origin. Cisgender ally attendees (n = 29) were heterosexual (48%), gay/lesbian (17%), and bisexual/pansexual/queer (28%).	Y	Y	13 +	125	Arkansas	9	2.26
Rhodes et al. ⁶⁹	Qualitative	Transgender health	Immigrant Latina transgender women. All were originally from Mexico. Mean number of years living in the United States was 10.	NR	Y	22–45	9	North Carolina	8	2.48
Boggs et al. ⁴⁷	Qualitative	Older adult services	Participants from at least one data collection event: intercept surveys (n = 17); focus groups (n = 14); town hall meeting (n = 30); or final interview (n = 12). Mostly gay males in their 70s and lesbian females in their 60s.	Y ^a	Y ^a	40–79	73	Denver, CO	7	1.95

(continued)



Table 2. (Continued)

Abbreviated citation	Study design	Primary topic area	Sample description	Inclusion			Age, range	Total, N	Study setting	No. of community involvement elements (0–13)	Average quality score (0–3)
				Bisexual	TGN	Y ^a					
Bryant et al. ⁴⁸	Qualitative	Substance use	The focus groups included a total of 36 participants, who were 42% African American, 58% White, 58% gay male, 36% lesbian, and 6% transgender (male-to-female). Groups organized by smoking status: current smokers, former smokers, and nonsmokers. Thirty participants involved in community meeting.	NR	Y ^a	23–58	66	Atlanta, GA	7	2.14	
Felner et al. ⁵¹	Qualitative	Youth services Health care access	11 youth researchers, most were people of color and all were LGBTQ; 26 current and former LGBTQ service patrons; and 10 LGBTQ service providers at 1 of 6 services.	Y	Y ^a	18–24	48	Chicago, IL	7	2.41	
Felner et al. ⁵²	Qualitative	Youth services	LGBTQ young adults (N=26) who utilize support network in Chicago and service providers (N=10) at LGBTQ-supportive youth programs. Focus group participants were mostly Black and/or African American (80%) and male (58%).	Y	Y ^a	Focus group: 20–29	36	Chicago, IL	7	2.45	
Rhodes et al. ⁷⁰	Randomized controlled trial	HIV/AIDS	Immigrant Spanish-speaking Latinx GBMSM and TW social network members. Most participants were foreign born. 66.3% speaking only/mostly Spanish. Foreign-born participants had been living in the United States for a mean of 10.1 years. Seventy-three percent were undocumented. Eighty percent gay, 16% bisexual, 11% transgender.	Y	Y	18–48	166	North Carolina	7	2.39	
Schnarrs et al. ⁷⁹	Cross-sectional	Sexual health	Rural MSM; 55% gay, 20% bisexual, 17% heterosexual. Participants were White (89.6%), African American/Black, Asian/Pacific Islander (1.3%) or of another race (2.6%), and Hispanic/Latino (2.3%). The majority (81.2%) resided in the largest city (population of 69,291 persons), with the remaining from surrounding communities of that area (12.0%).	Y	N	18–67	309	Rural Indiana	7	1.86	
Hergenrather et al. ⁵⁵	Non-randomized experimental	HIV/AIDS	African American men, who were gay and unemployed, participated.	N	N	37–57	7	Washington, DC	6	2.26	

(continued)



Table 2. (Continued)

Abbreviated citation	Study design	Primary topic area	Sample description	Sample			Study setting	No. of community involvement elements (0–13)	Average quality score (0–3)	
				Inclusion		Age, range				
				Bisexual	TGN					Total, N
Peister et al. ⁶⁵	Cross-sectional	Substance use	Participants were 59% male, 75% homosexual, 90.2% White, 93.8% non-Hispanic. A small percentage were either Alaskan native/American Indian (4.8%) or Asian (0.7%).	Y	Y	19–70	763	Nebraska	6	2.30
Rhodes et al. ⁷⁶	Quasi-experimental	HIV/AIDS	Participant of an online chat room for MSM; 58% were gay; 18% were bisexual; 24% did not report sexual identity. The majority were White/European (71%); and 1.6% reported HIV positivity.	Y	N	18–78	346	Northwest North Carolina	6	2.26
Rodriguez-Diaz et al. ⁷⁷	Cross-sectional	Health care access	LGBT Pride Parade participants. 59.7% were male and 39.9% female. One person was transgender. 56.0% identified as gay, 34.5% lesbian, 7.8% bisexual, and 1.7% other.	Y	Y ^a	18–63	233	San Juan, Puerto Rico	6	1.86
Solorio et al. ⁸²	Qualitative	HIV/AIDS	Latino immigrant MSM, more than 75% Mexican descent; Spanish-speaking (monolingual). Most resided in the United States for <5 years.	N	N	18–40	66	Seattle, Washington	6	2.26
Martinez et al. ⁵⁹	Qualitative	Sexual health	25 non-Latino White, 25 non-Latino Black, and 25 Latino men. All men identified as “behaviorally bisexual.” Nearly all men (96%) were born outside the United States. In addition, most men (72%) originally migrated to the United States from urban areas, and most (72%) had been living in the United States for <10 years.	Y	N	19–70	25	Indianapolis and the surrounding catchment area	5	2.00
Rhodes et al. ⁷¹	Qualitative	HIV/AIDS	Immigrant Latino MSM. Over 85% reported Mexico as their country of origin. Majority was “gay” or “homosexual,” two were “bisexual,” and one was “heterosexual.” Four participants reported sex with both women and men during the past 3 months. Three participants were HIV positive; and two were male-to-female transgender.	Y ^a	Y ^a	18–48	21	Rural North Carolina	5	2.36

(continued)



Table 2. (Continued)

Abbreviated citation	Study design	Primary topic area	Sample description	Inclusion		Age, range	Total, N	Study setting	No. of community involvement elements (0–13)	Average quality score (0–3)
				Bisexual	TGN					
				Sample						
Rhodes et al. ⁷³	Qualitative	Sexual health	Nine focus groups include MSM participants (n = 88) who were African American/Black (n = 28), Hispanic/Latino (n = 33), White (n = 21), and biracial/ethnic (n = 6). Community forum attendees included community members (n = 4), service organization leaders (n = 15), and others; two historically Black colleges (n = 3); and two academic research institutions (n = 4). Included males and females, gay and non-gay attendees.	N	N	18–60	122	Northwest and Central North Carolina	5	2.10
Van Wagenen et al. ⁹⁰	Qualitative	Older adult services	LGBT adults age 60 and older. Half the sample was female; one was transgender. The vast majority (91%) of the sample was gay or lesbian, one was bisexual, and one was heterosexual. Eighteen percent were African American, remainder NHW.	Y ^a	Y ^a	60–80	22	Boston, MA	5	1.91
Alio et al. ⁴⁴	Qualitative with survey	HIV/AIDS	Leaders and prominent members of the House Ball Community; African American, Latino, Afro-Latino or Afro-Caribbean, MSM or Transgender female.	Y ^a	Y ^a	25.4	14	Rochester/Buffalo region of New York	4	2.27
Alonzo et al. ⁴⁵	Randomized, controlled intervention with qualitative data	HIV/AIDS	Hispanic/Latino MSM or Hispanic/Latina transgender women.	Y	Y	18–55	152	North Carolina, USA	4	1.79
Hussen et al. ⁵⁶	Qualitative	HIV/AIDS	Young, Black gay or bisexual MSM (N = 29) and health care or social service providers (N = 28).	Y	N	18–29	57	Not reported	4	2.14
Mountz ⁶²	Qualitative	Youth services Transgender health	LGBT youth of color with the experience of having been incarcerated in a “girls” juvenile justice facility.	Y	Y	18–25	10	New York City and Dutchess County	4	2.27

(continued)



Table 2. (Continued)

Abbreviated citation	Study design	Primary topic area	Sample description	Inclusion		Age, range	Total, N	Study setting	No. of community involvement elements (0–13)	Average quality score (0–3)
				Bisexual	TGN					
				Y ^a	Y ^a					
Vissman et al. ⁹¹	Qualitative	Health care access	Latino community members and health service providers. Community members: 20 (56%) men, 14 (39%) women, and 2 (6%) male-to-female transgender participants. Seven men were gay. 69.4% were born in Mexico and 13.9% in the United States; others were foreign born outside Mexico. Service providers: one physician and one pharmacist serving mostly rural Latinos living in NC, one AIDS case manager, one domestic violence case manager, one medical interpreter for a local public health department, and one community health educator.	NR	Y ^a	23–64	36	Five rural counties in central NC	4	2.15
Reif et al. ⁶⁸	Pilot feasibility study	HIV/AIDS Mental health	Individuals living with HIV and a mental health disorder; 35% female; 80% African American.	N	N	NR	40	Charlotte, North Carolina	3	2.19
Rhodes et al. ⁷⁵	Cross-sectional	Sexual health Substance use	Rural immigrant Latino MSM, nearly 80% from Mexico. Sixteen percent transgender; 89% gay, 10% bisexual.	Y	Y	18–48	190	Rural North Carolina	3	2.24
Salkas et al. ⁷⁸	Cross-sectional	Transgender health Health care access	Transmasculine (n=31) and transfeminine (n=46) participants. 7.8% people of color.	NR	Y	NR	77	Online survey recruitment through Wisconsin-based venues/groups New England	3	1.64
Stover et al. ⁸⁴	Qualitative	Health care access	Students from 13 colleges/universities. Cisgender college students were lesbian (n=7), gay (n=7), and bisexual (n=4; all females).	Y ^a	N	19–24	18		3	1.70
Strang et al. ⁸⁵	Qualitative	Transgender health Youth services	Autistic/neurodiverse gender-diverse youth (n=31) and their parents (n=46) connected to services at a large medical center. Parents were 30 mothers and 16 fathers; 15 of these parents, all in heterosexual relationships, participated as couples. Of participating youth, 16 were trans-female, 11 trans-male, and 4 non-binary-transgender (assumed female at birth). Twenty-seven youth were White, two Asian, two mixed-race, and two Hispanic/Latinx. Input from key stakeholders or expert clinical providers was obtained but they were not involved in the intervention.	NR	Y	Youth: 12–19	77	Washington DC	3	2.32
Kattari et al. ⁵⁸	Cross-sectional	Transgender health Mental health	TGD adults.	Y	Y	28.6	659	Michigan	2	2.09

(continued)



Table 2. (Continued)

Abbreviated citation	Study design	Primary topic area	Sample				Study setting	No. of community involvement elements (0–13)	Average quality score (0–3)	
			Sample description	Inclusion		Age, range				Total, N
				Bisexual	TGN					
Noonan et al. ⁶⁴	Qualitative	Transgender health Health care access	University of Louisville School of Medicine faculty, staff, medical students, community health professionals, and community members. Fifty-nine participants in the forum and 100 completed follow-up survey.	NR	Y	NR	159	Louisville	2	2.08
Sun et al. ⁸⁶	Cross-sectional	Mental health	Immigrant adult Latino sexual minority men or transgender women. Average time in United States 10.1 years, 80.6% male, others female, male-to-female transgender, or transvesti.	N	Y	18–61	186	North Carolina	2	2.32
Sun et al. ⁸⁷	Cross-sectional	Sexual health	Participants were MSM and/or transgender adults. Most were White (82.3%) and male (98.7%). Included gay (45%), bisexual (40.7%), and heterosexual/other (13.6%) participants.	Y	Y	18–74	457	Four metropolitan areas across North Carolina	2	2.14
Tanner et al. ⁸⁸	Cross-sectional	Health care access	Immigrant Latino gay and bisexual men, MSM, and transgender people. Included community lay health advisors (<i>Navegantes</i>) and participants from the social network of Navegantes. 18.3% of the population identified as transgender.	N	Y	18–61	180	North Carolina	2	2.18
Hardacker et al. ⁵⁴	Qualitative	Physical health	Adults were assigned female gender at birth and now identify as gender non-conforming, queer, transgender men, lesbian, or bisexual. A small percentage were either Alaskan native/American Indian (2.8%) or Asian (8.3%).	Y	Y	18–64	36	Not reported	1	2.09
Irwin et al. ⁵⁷	Cross-sectional	Mental health	LGBT adults.	NR	Y	19–70	770	Nebraska and Iowa	1	2.27
Proctor and Krusen ⁶⁷	Qualitative	Older adult services	Older LGBTQ veterans.	Y ^a	Y ^a	51–87	7	Pacific Northwest	1	1.43
Rhodes et al. ⁷⁴	Qualitative	HIV/AIDS	Randomly selected GBMSM and TW with HIV who had completed an intervention to improve HIV care engagement participated in the interviews. Six participants were Black/African American, five were Spanish-speaking Latinx, and four were White. Gay (14) and bisexual (1).	Y ^a	N	Mean age 28	15	Guilford County, NC	1	2.10
Schnarrs et al. ⁸⁰	Cross-sectional	Mental health Physical health	27.2% TGD; gay (37.8%), lesbian (25.8%), bisexual/pansexual (26%), other sexuality (10.4%); White (36.7%), Latinx/Hispanic (45.3%), Black/African American (7.1%); Other race (10.9%)	Y	Y	18+	477	San Antonio, TX	1	2.05

(continued)



Table 2. (Continued)

Abbreviated citation	Study design	Primary topic area	Sample description	Inclusion		Age, range	Total, N	Study setting	No. of community involvement elements (0–13)	Average quality score (0–3)
				Bisexual	TGN					
				Sample						
Teti et al. ⁸⁹	Qualitative	Mental health Physical health Transgender health	Participants were transmasculine young adults who had not undergone surgical procedures. Fourteen were White, one Hispanic, and one Black. Culturally diverse SGMY at three high schools were Hispanic (n = 14), Haitian (n = 7), African American (n = 4), and other Caribbean (n = 3). Participants were female (n = 23), male (n = 4), and other (n = 1). Sexual orientations were bisexual (n = 12), lesbian (n = 7), mostly heterosexual (n = 5), gay (n = 3), and pansexual (n = 1). Informed stakeholders (n = 6), including clinicians, service providers working with SGMY in South Florida.	NR	Y	19–25	16	Small Midwestern city	1	1.50
Austin and Craig ⁴⁶	Qualitative	Youth services		Y	NR	<18	34	Miami, Florida	0	1.94
Edelman et al. ⁴⁹	Qualitative	HIV/AIDS	Local community medical case managers (n = 14), disease intervention specialists (n = 7), and MSM (n = 24).	Y	N	42.5	45	Connecticut	0	2.50
Edelman et al. ⁵⁰	Qualitative	HIV/AIDS Substance use	Medical case managers (n = 14), disease intervention specialists (n = 7), and MSM (n = 17).	Y	N	46	38	Connecticut	0	2.44
Fisher et al. ⁵³	Cross-sectional	Substance use Physical health	Participants (N = 723) were from Nebraska and Council Bluffs, Iowa. The majority of participants resided in an urban area (89.5%) and were White (91.6%). Rural participants (n = 75) were predominantly male (n = 49, 65.3%) and White (n = 71, 95.9%). A small percentage were either Alaskan native/American Indian (0.8% or Asian 0.9%). More rural participants were bisexual (21.3% vs. 15.9%), while rates of transgender identity were similar between rural and urban populations (10.7% vs. 10.8%). All persons who were heterosexual also were transgender.	Y	Y	19+	723	Nebraska and Iowa	0	2.14
Martinez-Velez et al. ⁶⁰	Cross-sectional	Transgender health Health care access	Transgender and gender non-conforming individuals.	Y ^a	Y	15–49	52	Puerto Rico	0	2.05
Meyer et al. ⁶¹	Qualitative	Transgender health Health care access	TGD adults.	NR	Y	22–64	27	Nebraska	0	2.09
Mountz et al. ⁶³	Qualitative	Youth services Transgender health	TGD youth with experience in the foster care system. All were racial/ethnic minorities.	Y	Y	18–25	7	Los Angeles, California	0	1.64

^aY* = yes n ≤ 5.

GBMSM, gay, bisexual and other men who have sex with men; LGBTQ, lesbian, bisexual, transgender, queer; MSM, men who have sex with men; N, not included; NR, not reported; SGMY, sexual or gender minority youth; TGD, transgender and gender diverse; TW, transgender women; Y, yes.



Study quality

Among the 28 qualitative studies included in this review, the average quality rating ranged from 1.43 to 2.5, with an average score of 2.32. Among the 15 cross-sectional studies included in this review, the average quality rating ranged from 1.64 to 2.27, with an average score of 2.08.

Study characteristics

Participants. Study sample size ranged from 7 to 763 participants (Table 2). Three studies (6.3%) exclusively included older adults, although the lower age limit for “older adult” ranged from 40 to 60 years old.^{47,67,90} Sixteen studies (33.3%) exclusively included the perspectives of people of color (POC); one of these recruited only Black men who have sex with men living with HIV,⁵⁵ and nine focused on the health of Latinx SGM individuals. In an additional eight studies (14.6%), White non-Hispanic participants were the minority.

There was a wide variety of SGM identities represented within the 48 included studies. As seen in Table 2, 32 studies (66.7%) included bisexual participants, although 9 of these had 5 or less bisexual participants. Ten studies (20.8%) included lesbian participants, but no study focused solely on experiences of these women. More than half of studies in this review ($n=33$, 68.8%) included transgender/gender non-conforming (TGNC) individuals. Nine of these included exclusively TGNC participants and 10 included 5 or less TGNC participants.

Primary topic. Reviewed studies covered nine primary topics (Table 1). The most commonly addressed were HIV/AIDS (12/48, 25%) and transgender health (12/48, 25%). Access to health care was also commonly explored (8/48, 16.8%). Four studies (8.3%) specifically address older SGM health services, and six studies (12.5%) addressed SGM youth services. Other health topics examined included: physical health (four studies; 8.3%), sexual health (five studies; 10.4%), mental health (seven studies; 14.6%), and substance use (six studies; 12.5%). Sixteen of the studies addressed two primary topics (33.3%).

Funding source. A sizable proportion of studies (29.2%) reported no funding source (Table 1). Five (10.4%) had three or more funding sources, eight studies (16.7%) had two funding sources, and one study (2.1%) had one funding source. Of the funded studies, 25 (52.1%) received Federal funding, 3 received State

funding (6.3%), 20 were funded through university mechanisms (41.7%), and 8 (16.7%) received funding from private foundations or other sources.

Elements of community involvement reported

Within the reviewed CBPR studies, a wide range of community involvement was reported. The distinction between academic and community partners was not always precise because some descriptions of community partners included academic partners with SGM identities. The number of community elements incorporated ranged from 0 to 11, with seven studies not specifically describing any of the AHRQ-determined community involvement elements in their article. The study with the most community elements was a qualitative study examining health services among older adults.⁶⁶ Examples of elements were: selecting the research question; developing the research proposal; collecting the data and other implementation activities; interpreting, disseminating, and applying the findings.

The most commonly reported community involvement elements were recruitment (56.3%) and study design (52.1%) (Table 3). Furthermore, more than half (54.2%) reported community partners assisting with interpretation of the findings. The research question of 21 projects (43.8%) was selected in partnership with community members, but only 3 (6.3%) study proposals were developed with community partner input. A small majority (4.2%) described community partners assisting with retaining the participants. No study reported shared financial responsibility with community members.

Table 3. Community Involvement in Sexual and Gender Minority Health Community-Based Participatory Research Studies ($n=48$)

Element of community involvement	Number of studies (%)
Recruit subjects	27 (56.3)
Interpret findings	26 (54.2)
Design study	25 (52.1)
Develop surveys/instruments	24 (50)
Select research question	21 (43.8)
Data collection	19 (39.6)
Disseminate findings	14 (29.2)
Apply findings	13 (27.1)
Develop interventions	11 (22.9)
Implement interventions	5 (10.4)
Develop proposal	3 (6.3)
Retain subjects	2 (4.2)
Have financial responsibility	0 (0)



Discussion

Despite wider recognition of the value of community-academic partnerships in SGM health research over the past decade, this work remains sparse and adherence to the CBPR framework is variable given inherent challenges and an understanding that a single set of principles may not be appropriate for all communities and all contexts.⁴ On the continuum of community-engaged research, CBPR moves beyond community involvement and collaboration and signifies the highest level of engagement. It is hallmarked by shared leadership and a strong and sustained partnership that ideally integrates the community into each phase of the project.⁹² Of the 48 studies identified in this review, none met this standard. No study included all 13 community involvement elements identified in the 2004 AHRQ report, and 7 studies included none at all.^{46,49,50,53,60–62}

Of note, only those elements described in the articles were assessed, and it may be likely that limitations such as article word limits may account for incomplete descriptions of methods and community involvement. Among the four studies with the greatest number of elements, the quality varied, with no study achieving an optimal assessment score.^{60,69,81,83}

Considering all studies, community involvement was disproportionately concentrated in the study design, recruitment, instrument development, and interpretation of results. In most cases, the community did not select the research topic and/or the research question, an activity essential to creating a shared vision and ensuring the project is community driven. Excluding the community at this critical point can limit identification of priorities and outcomes most important to them and instead promote the researcher's agenda and expertise or the funder's priorities.² Diminishing bidirectional collaboration and power sharing also damages the community–researcher relationship and can create a climate that the community does not perceive as open and just. This impacts not only the active study but also may propagate sentiments of distrust that negatively impact future research efforts.

There was limited evidence that studies prioritized removing barriers to community participation. The most commonly reported strategies included the provision of monetary incentives and transportation assistance (i.e., bus pass). Although these may address some challenges, other social and structural barriers may also impede participation of community members in the research process. Academic partners have the

opportunity to build community capacity by providing education and resources for navigating research processes (Table 4).

Defining “community” was critical to understanding how authentically each study's findings may have represented the SGM experience. We therefore limited our definition of community to include SGM individuals representing the community to be served by the research efforts. In several studies reviewed, researchers and/or community advisory board members included stakeholder groups such as SGM service organizations and clinical providers treating SGM patients; this alone was not sufficient to warrant community involvement.

Difficulty in recruiting a sufficient number of SGM community members is not unusual in health research, particularly when working in a small geographically defined community or with some subpopulations (e.g., TGNC). In this case, supplementing the community member group with relevant community leaders and stakeholders can be helpful. Similarly, some studies focused on exploration of topics for which the health care and/or service provider perspective was relevant.

Table 4. Recommendations for the Advancement of Sexual and Gender Minority Community-Based Participatory Research

For researchers	
Prioritize removing barriers to community participation	<i>Hold meetings in community-accessible locations at amenable times</i> <i>Provide education and resources for navigating the research process</i>
Involve the community in selection of research topic/question	<i>With special consideration of less explored areas: demographic research, intervention research, social influences, and health inequities</i>
Pay thoughtful attention to intersectional effects of marginalized identities	<i>Use demographic measurement tools that account for the vast diversity within the LGBTQ+ community</i>
Supplement, but do not replace, a community member of lived experience with relevant community partner(s) and stakeholder(s)	
Ensure capacity building, partnership sustainability, and use of findings for policy change	
For academic institutions	
Allow for promotion/tenure timetable alternatives with CBPR engagement	
Invest in fostering sustainable community-academic partnerships	
Require curriculum training in community-based research methodology	
For funders	
Move beyond the rigid model of preprogram budgets	
Offer flexible funding opportunities to support extended time needed in CBPR	
Enable greater flexibility in the choice of topics	
Increase availability of funding models with multiple streams, alternative deliverables, and structures with flexibility to adapt to emerging community needs	

CBPR, community-based participatory research.



But because it could not be assumed that all stakeholders who participated were well qualified to speak with authority about the SGM experience, if no SGM community members with lived experience with the health topic of interest were involved in a particular study element, credit was not given for that element.

SGM POC, bisexual, and transgender people remain inadequately represented on the general SGM health landscape. Within CBPR studies, however, a greater proportion of these populations were represented. Twenty-five studies reported mostly or entirely POC samples, with significant representation of Latinx and Black/African American participants. Over half of studies included bisexual participants, although only one focused exclusively on bisexual health despite evidence that most sexual minority adults, particularly younger cohorts, identify as bisexual.⁹³ Twenty-five percent examined transgender mental health and health care use and access experiences. Few studies, however, included gender diverse participants such as genderqueer, gender non-binary, and gender non-conforming individuals.^{54,60,66,83} Intersectional perspectives of some groups such as immigrant Latinas, juvenile justice-involved girls, and autistic and neurodiverse youth were also included.

Despite these strengths in representation, inconsistencies in SOGI conceptualization, measurement, and operationalization were observed across studies. Variations were likely influenced by study timing (i.e., language reflective of conventions of the time), geographic region, and knowledge and preferences of research teams (it is unclear if SGM partner input was integrated as no studies explicitly reported this). For example, some studies recruited under the broad “LGBTQ” umbrella without disaggregating sexuality and gender subgroups.^{51,52,62,67,80} Sex and gender are often mistakenly conflated with the assumption that they do not differ from each other.

Of note, only two studies explicitly reported representation of indigenous third gender/non-binary roles (i.e., two-spirit, fa’afafine, māhū).^{62,81} Our operationalization of SOGI was not entirely inclusive, and the search structure used missed relevant publications as we failed to include the appropriate MeSH terms and keywords—a major limitation. In addition, it is likely that people who endorsed these identities comprised a small proportion of total participants in included studies and were reported under “other” and “additional” SOGI categories.

Aggregating the diversity under the LGBTQ+ umbrella risks mischaracterizing experiences of power,

sexuality, and relations. SOGIs are core aspects that shape opportunities and experiences of discrimination that influence health; therefore, accurate conceptualization and measurement is crucial. Continued efforts have been made to improve measurement of sex, gender, and sexual orientation, most recently, the groundbreaking 2022 National Academies of Science, Engineering, and Medicine report.⁹⁴ This report is the most comprehensive to date of measurement-related research for these constructs. As utilization of these recommendations permeate the research community, data collection can be enhanced, demonstrating respect to and making visible the SGM participant, partner, or patient. Dissemination will also enable data harmonization between data sources, further building the bodies of work that will inform future health interventions and practice.

SGM CBPR health research covers a range of topics. Although our definition of “health” research was expansive enough to include topics such as mental health and SDOH, it is possible that other relevant health-related topics were excluded from consideration, limiting the results. In addition, we did not search gray literature, which might have resulted in the identification of additional studies that would have been eligible for inclusion. In studies identified there was a concentration in HIV/AIDS, reflective of patterns in SGM health research overall. More research is needed in a large number of diverse areas, including demographic research, intervention research, social influences, and health inequities.²⁸ Use of CBPR can play a key role in addressing these gaps, particularly exploration of approaches to addressing the SDOH.²

The majority of studies reviewed were exploratory or descriptive with either a qualitative or cross-sectional survey design. This decreased overall community involvement scores as credit could not be given for activities such as intervention implementation or participant retention. In addition, capacity building, partnership sustainability, and use of findings for policy change were commonly lacking, independent of study design. These are significant and interrelated gaps. Moving the needle from exploratory to interventional research can provide a foundation of growth, sustainability, and innovation within a community that over time can enable transformational change to occur. To facilitate this shift, commitment from funders—particularly those of federal mechanisms—is integral.

CBPR studies are often unfunded, as was the case for 30% of studies in this review, or funded by smaller



mechanisms, offering little-to-no incentive or sustainable support to engage in robust CBPR work. Adequate and flexible funding opportunities are needed to support the extended time needed upfront to build relationships with community partners, as well as the additional time—months or years—often involved as the community participation process evolves. Increased success has been demonstrated in programs that have had access to “braided funding” from multiple streams, a model that affords more flexibility in terms of concrete “deliverables” and provides programs the authority to fund efforts that are based on emerging community needs.⁹⁵ Similar flexibility should be explored and expanded in other government and foundation research grant programs to move beyond the rigid model of preprogram budgets.

Other structural and educational barriers to CBPR work have been documented (Table 4) and may have limited CBPR projects included in our review. For example, the typical timetable for promotion and tenure at academic institutions may not be amenable to the pursuit of CBPR as this methodology is more time-consuming than traditional research approaches. Researchers must contend with the time required to build sustainable partnerships and recruit and train community researchers, shifts in community priorities and leadership, and other unanticipated hurdles.^{96,97}

In addition, although public health juggernauts such as the Institute of Medicine encourage academic researchers to foster community-academic partnerships that share the strengths of each and call for CBPR to be included among traditional curricula,^{98,99} most graduate programs do not require training in community-based research methodology. This may limit acceptability of CBPR as a viable, academically acceptable option. It certainly restricts the ability of untrained academic practitioners to effectively conduct CBPR research.¹⁰⁰

Conclusion

Implementing the CBPR framework with true fidelity is challenging. Across studies we found wide variation in the extent to which communities were involved in research activities, reflecting the diversity of CBPR partnerships, settings where SGM health research is conducted, and the inherent difficulty in adhering to the model. Although achieving a perfect score on the CBPR principles is difficult, if not impossible, the framework represents targets to strive for in the pursuit for more equitable and collaborative research con-

ducted in SGM communities. Prioritizing this work can have a transformational impact on reducing the fundamental inequities that threaten SGM health.

Authors' Contributions

J.M.R.: Conceptualization, methodology, formal analysis, writing—original, writing—review and editing, project administration; E.K.A.: Conceptualization, methodology, formal analysis, writing—original, writing—review and editing, project administration; S.D.S.: Conceptualization, methodology, formal analysis, writing—original, writing—review and editing, visualization; R.A.Y.: Conceptualization, methodology, formal analysis, writing—original, writing—review and editing, visualization; A.M.A.: Conceptualization, methodology, formal analysis, writing—original, writing—review and editing, visualization; D.A.-D.: Conceptualization, methodology, formal analysis, writing—original, writing—review and editing.

Author Disclosure Statement

No competing financial interests exist.

Funding Information

No funding was received for this article.

Supplementary Material

Supplementary Appendix SA1
Supplementary Appendix SA2
Supplementary Appendix SA3

References

1. Wallerstein N, Duran B, Oetzel J, et al. *Community-Based Participatory Research for Health*, 3rd ed. San Francisco: Jossey Bass, 2017.
2. Blumenthal DS. Is community-based participatory research possible? *Am J Prev Med*. 2011;40:386.
3. Vaughn LM. Community-based participatory research: focus on children and adolescents. *Fam Community Health*. 2015;38:1–2.
4. Israel BA, Schulz AJ, Parker EA, et al. Critical issues in developing and following community based participatory research principles. In: *Community Based Participatory Research for Health: From Research to Outcomes*. Edited by Minkler M, Wallerstein N. San Francisco, CA: Jossey-Bass, 2003, pp. 53–76.
5. Minkler M, Wallerstein N, eds. *Community Based Participatory Research for Health: From Research to Outcomes*. San Francisco: Jossey-Bass, 2003.
6. Jagosh J, Macaulay AC, Pluye P, et al. Uncovering the benefits of participatory research: implications of a realist review for health research and practice. *Milbank Q*. 2012;90:311–346.
7. Barrera M, Castro FG, Steiker LKH. A critical analysis of approaches to the development of preventive interventions for subcultural groups. *Am J Community Psychol*. 2011;48:439–454.
8. Eriksen M, Rothenberg R. Community-based participatory research (CBPR). Editorial. *Health Educ Res*. 2012;27:553–554.
9. Olshansky E, Zender R. The use of community-based participatory research to understand and work with vulnerable populations. In: *Caring for the Vulnerable: Perspectives in Nursing Theory, Practice and Research*. Edited by de Chesnay M, Anderson BA. Burlington, MA: Jones & Barlett, 2008, pp. 269–275.



10. Olshansky E, Sacco D, Braxter B, et al. Participatory action research to understand and reduce health disparities. *Nurs Outlook*. 2005;53:121–126.
11. Lofman P, Pelkonen M, Pietila AM. Ethical issues in participatory action research. *Scand J Caring Sci*. 2004;18:333–340.
12. Newport F. In U.S., Estimate of LGBT Population Rises to 4.5%. GALLUP. May 22, 2018. Available at: <https://news.gallup.com/poll/234863/estimate-lgbt-population-rises.aspx> Accessed October 1, 2021.
13. Patterson CJ, D'Augelli AR, eds. *Handbook of Psychology and Sexual Orientation*. New York, NY: Oxford University Press, 2013.
14. National Academies of Sciences, Engineering, and Medicine. *Understanding the Well-Being of LGBTQI+ Populations*. Washington, DC: The National Academies Press, 2020.
15. Winter S, Diamond M, Green J, et al. Transgender people: health at the margins of society. *Lancet*. 2016;388:390–400.
16. Cyrus K. Multiple minorities as multiply marginalized: applying the minority stress theory to LGBTQ people of color. *J Gay Lesbian Ment Health*. 2017;21:194–202.
17. Meyer IH. Prejudice, social stress, and mental health in lesbian, gay, and bisexual populations: conceptual issues and research evidence. *Psychol Bull*. 2003;129:674–697.
18. James SE, Herman J, Keisling M, et al. 2015 U.S. Transgender Survey. Inter-University Consortium for Political and Social Research. 2019; doi: 10.3886/ICPSR37229.v1.
19. Hulbert-Williams NJ, Plumpton CO, Flowers P, et al. The cancer care experiences of gay, lesbian and bisexual patients: a secondary analysis of data from the UK Cancer Patient Experience Survey. *Eur J Cancer*. 2017;26:e12670.
20. Goldhammer H, Maston ED, Kissock LA, et al. National findings from an LGBT healthcare organizational needs assessment. *LGBT Health*. 2018;5:461–468.
21. Crenshaw KW. Mapping the margins: intersectionality, identity politics, and violence against women of color. *Stanford Law Rev*. 1991;43:1241–1299.
22. Fredriksen-Goldsen KI, Shiu C, Bryan AE, et al. Health equity and aging of bisexual older adults: Pathways of risk and resilience. *J Gerontol B Psychol Sci Soc Sci*. 2017;72:468–478.
23. Fredriksen-Goldsen KI, Kim H-J, Emlert CA, et al. *The Aging and Health Report: Disparities and Resilience among Lesbian, Gay, Bisexual, and Transgender Older Adults*. Seattle, WA: Institute for Multigenerational Health, 2011.
24. Lee JJ, Katz DA, Glick SN, et al. Immigrant status and sexual orientation disclosure: implications for HIV/STD prevention among men who have sex with men in Seattle, Washington. *AIDS Behav*. 2020;24:2819–2828.
25. ACT UP <https://actupny.com/> Accessed June 23, 2022.
26. Minkler M, Wallerstein N, eds. *Community-Based Participatory Research for Health: From Process to Outcomes*. San Francisco: Jossey-Bass, 2003.
27. National Institutes of Health. Sexual and Gender Minority Research Office. 2021–2025 Strategic Plan to Advance Research on the Health and Well-being of Sexual & Gender Minorities. Available at: https://dpcpsi.nih.gov/sites/default/files/SGMStrategicPlan_2021_2025.pdf Accessed October 1, 2021.
28. Institute of Medicine Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities. *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*. Washington (DC): National Academies Press (US), 2011.
29. Leung MW, Yen IH, Minkler M. Community based participatory research: a promising approach for increasing epidemiology's relevance in the 21st century. *Int J Epidemiol*. 2004;33:499–506.
30. Minkler M. Community-based research partnerships: challenges and opportunities. *J Urban Health*. 2005;82:ii3–ii12.
31. Ehde DM, Dillworth TM, Turner JA. Cognitive-behavioral therapy for individuals with chronic pain: efficacy, innovations, and directions for research. *Am Psychol*. 2014;69:153–166.
32. Wali S, Superina S, Mashford-Pringle A, et al. What do you mean by engagement?—evaluating the use of community engagement in the design and implementation of chronic disease-based interventions for Indigenous populations—scoping review. *Int J Equity Health*. 2021;20:8.
33. Manjunath C, Ifelayo O, Jones C, et al. Addressing cardiovascular health disparities in Minnesota: establishment of a Community Steering Committee by FAITH! (Fostering African-American Improvement in Total Health). *Int J Environ Res Public Health*. 2019;16:4144.
34. Mann-Jackson L, Alonzo J, Garcia M, et al. Using community-based participatory research to address STI/HIV disparities and social determinants of health among young GBMSM and transgender women of colour in North Carolina, USA. *Health Soc Care Community*. 2021;29:e192–e203.
35. Guillot-Wright S, Farr NM, Cherryhomes E. A community-led mobile health clinic to improve structural and social determinants of health among (im)migrant workers. *Int J Equity Health*. 2022; 21:58.
36. Tou LC, Prakash N, Jeyakumar SJ, et al. Investigating social determinants of health in an urban direct primary care clinic. *Cureus*. 2020;12:e10791.
37. Trinh-Shevrin C, Kwon SC, Park R, et al. Moving the dial to advance population health equity in New York City Asian American populations. *Am J Public Health*. 2015;105(Suppl 3):e16–e25.
38. Bain AL, Payne WJ. Queer de-participation: reframing the co-production of scholarly knowledge. *Qual Res*. 2016;16:330–340.
39. Travers R, Pyne J, Bauer G, et al. 'Community control' in CBPR: challenges experienced and questions raised from the Trans PULSE project. *Action Res*. 2013;11:403–422.
40. Liberati A, Altman DG, Tetzlaff J, et al. The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate health care interventions: explanation and elaboration. *J Clin Epidemiol*. 2009;62:e1–e34.
41. PROSPERO. Centre for Reviews and Dissemination, University of York. Available at: www.crd.york.ac.uk/PROSPERO Accessed August 13, 2021.
42. Covidence Systematic Review Software. *Veritas Health Innovation*. Melbourne, Australia.
43. Viswanathan M, Ammerman A, Eng E, et al. Community-based participatory research: assessing the evidence. *Evid Rep Technol Assess (Summ)*. 2004;99:1–8.
44. Alio AP, Sibley C, Ouedraogo HS, et al. House Ball Community Leaders' perceptions of HIV and HIV vaccine research. *Int J MCH AIDS*. 2020;9: 136–145.
45. Alonzo J, Mann L, Tanner AE, et al. Reducing HIV risk among Hispanic/Latino men who have sex with men: qualitative analysis of behavior change intentions by participants in a small-group intervention. *J AIDS Clin Res*. 2016;7:572.
46. Austin A, Craig SL. Empirically supported interventions for sexual and gender minority youth. *J Evid Inf Soc Work*. 2015;12:567–578.
47. Boggs JM, Dickman Portz J, King DK, et al. Perspectives of LGBTQ older adults on aging in place: a qualitative investigation. *J Homosex*. 2017;64: 1539–1560.
48. Bryant L, Damarin AK, Marshall Z. Tobacco control recommendations identified by LGBT Atlantans in a community-based participatory research project. *Prog Community Health Partnersh*. 2014;8:269–279.
49. Edelman EJ, Cole CA, Richardson W, et al. Opportunities for improving partner notification for HIV: results from a community-based participatory research study. *AIDS Behav*. 2014;18:1888–1897.
50. Edelman EJ, Cole CA, Richardson W, et al. Stigma, substance use and sexual risk behaviors among HIV-infected men who have sex with men: a qualitative study. *Prev Med Rep*. 2016;3:296–302.
51. Felner JK, Dudley TD, Ramirez-Valles J. "Anywhere but here": querying spatial stigma as a social determinant of health among youth of color accessing LGBTQ services in Chicago's Boystown. *Soc Sci Med*. 2018;213: 181–189.
52. Felner JK, Dyette O, Dudley T, et al. Participatory action research to address aging out of LGBTQ-supportive youth programs in Chicago. *J LGBT Youth*. 2020;19:1–26.
53. Fisher CM, Irwin JA, Coleman JD. LGBT health in the midlands: a rural/urban comparison of basic health indicators. *J Homosex*. 2014;61:1062–1090.
54. Hardacker CT, Baccellieri A, Mueller ER, et al. Bladder health experiences, perceptions and knowledge of sexual and gender minorities. *Int J Environ Res Public Health*. 2019;16:3170.
55. Hergenrather KC, Geishecker S, Clark G, et al. A pilot test of the HOPE Intervention to explore employment and mental health among African American gay men living with HIV/AIDS: results from a CBPR study. *AIDS Educ Prev*. 2013;25:405–422.
56. Hussen SA, Jones M, Moore S, et al. Brothers building brothers by breaking barriers: development of a resilience-building social capital intervention for young black gay and bisexual men living with HIV. *AIDS Care*. 2018;30(Suppl 4):51–58.
57. Irwin JA, Coleman JD, Fisher CM, et al. Correlates of suicide ideation among LGBT Nebraskans. *J Homosex*. 2014;61:1172–1191.



58. Kattari SK, Kattari L, Johnson I, et al. Differential experiences of mental health among transgender diverse adults in Michigan. *Int J Environ Res Public Health*. 2020;17:6805.
59. Martinez O, Dodge B, Reece M, et al. Sexual health and life experiences: voices from behaviourally bisexual Latino men in the Midwestern USA. *Cult Health Sex*. 2011;13:1073–1089.
60. Martinez-Velez JJ, Melin K, Rodriguez-Diaz CE. A preliminary assessment of selected social determinants of health in a sample of transgender and gender nonconforming individuals in Puerto Rico. *Transgend Health*. 2019;4:9–17.
61. Meyer HM, Mocarski R, Holt NR, et al. Unmet expectations in health care settings: experiences of transgender and gender diverse adults in the Central Great Plains. *Qual Health Res*. 2020;30:409–422.
62. Mountz S. Remapping pipelines and pathways: listening to queer and transgender youth of color's trajectories through girls' juvenile justice facilities. *Affilia*. 2020;35:177–199.
63. Mountz S, Capous-Desyllas M, Pourciau E. 'Because we're fighting to be ourselves': voices from former foster youth who are transgender and gender expansive. *Child Welfare*. 2018;96:103–126.
64. Noonan EJ, Sawning S, Combs R, et al. Engaging the transgender community to improve medical education and prioritize healthcare initiatives. *Teach Learn Med*. 2018;30:119–132.
65. Pelster AD, Fisher CM, Irwin JA, et al. Tobacco use and its relationship to social determinants of health in LGBT populations of a Midwestern State. *LGBT Health*. 2015;2:71–76.
66. Perone AK, Ingersoll-Dayton B, Watkins-Dukhie K. Social isolation loneliness among LGBT older adults: lessons learned from a pilot friendly caller program. *Clin Soc Work J*. 2020;48:126–139.
67. Proctor AR, Krusen NE. Time to ask and tell: voices of older gay and bisexual male veterans regarding community services. *J Gay Lesbian Soc Serv*. 2017;29:415–425.
68. Reif SS, Pence BW, LeGrand S, et al. In-home mental health treatment for individuals with HIV. *AIDS Patient Care STDS*. 2012;26:655–661.
69. Rhodes SD, Alonzo J, Mann L, et al. Using photovoice, Latina transgender women identify priorities in a new immigrant-destination state. *Int J Transgend*. 2015;16:80–96.
70. Rhodes SD, Alonzo J, Mann-Jackson L, et al. A peer navigation intervention to prevent HIV among mixed immigrant status Latinx GBMSM and transgender women in the United States: outcomes, perspectives and implications for PrEP uptake. *Health Educ Res*. 2020;35:165–178.
71. Rhodes SD, Hergenrather KC, Aronson RE, et al. Latino men who have sex with men and HIV in the rural south-eastern USA: findings from ethnographic in-depth interviews. *Cult Health Sex*. 2010;12:797–812.
72. Rhodes SD, Hergenrather KC, Duncan J, et al. A pilot intervention utilizing Internet chat rooms to prevent HIV risk behaviors among men who have sex with men. *Public Health Rep*. 2010;125(Suppl 1):29–37.
73. Rhodes SD, Hergenrather KC, Vissman AT, et al. Boys must be men, and men must have sex with women: a qualitative CBPR study to explore sexual risk among African American, Latino, and White gay men and MSM. *Am J Mens Health*. 2011;5:140–151.
74. Rhodes SD, Mann-Jackson L, Alonzo J, et al. A rapid qualitative assessment of the impact of the COVID-19 pandemic on a racially/ethnically diverse sample of gay, bisexual, and other men who have sex with men living with HIV in the US South. *AIDS Behav*. 2021;25:58–67.
75. Rhodes SD, McCoy TP, Hergenrather KC, et al. Prevalence estimates of health risk behaviors of immigrant latino men who have sex with men. *J Rural Health*. 2012;28:73–83.
76. Rhodes SD, Vissman AT, Stowers J, et al. A CBPR partnership increases HIV testing among men who have sex with men (MSM): outcome findings from a pilot test of the CyBER/testing internet intervention. *Health Educ Behav*. 2011;38:311–320.
77. Rodríguez-Díaz CE, Martínez-Vélez JJ, Jovet-Toledo GG, et al. Challenges for the well-being of and health equity for lesbian, gay, and bisexual people in Puerto Rico. *Int J Sex Health*. 2016;28:286–295.
78. Salkas S, Conniff J, Budge SL. Provider quality and barriers to care for transgender people: an analysis of data from the Wisconsin trans-gender community health assessment. *Int J Transgend*. 2018;19:59–63.
79. Schnarrs PW, Rosenberger JG, Satinsky S, et al. Sexual compulsivity, the Internet, and sexual behaviors among men in a rural area of the United States. *AIDS Patient Care STDS*. 2010;24:563–569.
80. Schnarrs PW, Stone AL, Salcido R Jr., et al. Differences in adverse childhood experiences (ACEs) and quality of physical and mental health between transgender and cisgender sexual minorities. *J Psychiatr Res*. 2019;119:1–6.
81. Smith AJ, Hallum-Montes R, Nevin K, et al. Determinants of transgender individuals' well-being, mental health, and suicidality in a rural state. *Rural Ment Health*. 2018;42:116–132.
82. Solorio R, Norton-Shelpuk P, Forehand M, et al. HIV Prevention messages targeting young Latino immigrant MSM. *AIDS Res Treat*. 2014;2014:353092.
83. Stewart MK, Archie DS, Marshall SA, et al. Transform health Arkansas: a transgender-led partnership engaging transgender/non-binary Arkansians in defining health research priorities. *Prog Community Health Partnersh*. 2017;11:427–439.
84. Stover CM, Hare P, Johnson M. Healthcare experiences of lesbian, gay, and bisexual college students: recommendations for the clinical nurse specialist. *Clin Nurse Spec*. 2014;28:349–357.
85. Strang JF, Knauss M, van der Miesen A, et al. A clinical program for transgender and gender-diverse neurodiverse/autistic adolescents developed through community-based participatory design. *J Clin Child Adolesc Psychol*. 2020;50:730–746.
86. Sun CJ, Ma A, Tanner AE, et al. Depressive symptoms among Latino sexual minority men and Latina transgender women in a New Settlement State: the role of perceived discrimination. *Depress Res Treat*. 2016;2016:4972854.
87. Sun CJ, Sutfin E, Bachmann LH, et al. Comparing men who have sex with men and transgender women who use Grindr, other similar social and sexual networking apps, or no social and sexual networking apps: implications for recruitment and health promotion. *J AIDS Clin Res*. 2018;9:757.
88. Tanner AE, Reboussin BA, Mann L, et al. Factors influencing health care access perceptions and care-seeking behaviors of immigrant Latino sexual minority men and transgender individuals: baseline findings from the HOLA intervention study. *J Health Care Poor Underserved*. 2014;25:1679–1697.
89. Teti M, Bauerband LA, Rolbiecki A, et al. Physical activity and body image: intertwined health priorities identified by transmasculine young people in a non-metropolitan area. *Int J Transgend Health*. 2020;21:209–219.
90. Van Wagenen A, Driskell J, Bradford J. "I'm still raring to go": successful aging among lesbian, gay, bisexual, and transgender older adults. *J Aging Stud*. 2013;27:1–14.
91. Vissman AT, Bloom FR, Leichter JS, et al. Exploring the use of non-medical sources of prescription drugs among immigrant Latinos in the rural Southeastern USA. *J Rural Health*. 2011;27:159–167.
92. McCloskey D, Aguilar-Gaxiola S, Michener J. CTSA Community Engagement Key Function Committee Task Force on the Principles of Community Engagement. Center for Disease Control (CDC). 2011. Available at: www.atsdr.cdc.gov/communityengagement/pce_ctsa.html Accessed November 30, 2021.
93. Jones JM. LGBT Identification Rises to 5.6% in Latest U.S. Estimate. GALLUP. February 24, 2021. Available at: <https://news.gallup.com/poll/329708/lgbt-identification-rises-latest-estimate.aspx> Accessed October 1, 2021.
94. National Academies of Sciences, Engineering, and Medicine. *Measuring Sex, Gender Identity, and Sexual Orientation*. Washington, DC: The National Academies Press, 2022.
95. El-Askari G, Freestone J, Irizarry C, et al. The Healthy Neighborhoods Project: a local health department's role in catalyzing community development. *Health Educ Behav*. 1998;25:146–159.
96. Calleson DC, Jordan C, Seifer SD. Community-engaged scholarship: is faculty work in communities a true academic enterprise? *Acad Med*. 2005;80:317–321.
97. Steiner BD, Calleson DC, Curtis P, et al. Recognizing the value of community involvement by AHC faculty: a case study. *Acad Med*. 2005;80:322–326.



98. Institute of Medicine. *Who Will Keep the Public Healthy?: Educating Public Health Professionals for the 21st Century*. Washington, DC: The National Academies Press, 2003.
99. Institute of Medicine. *The Future of the Public's Health in the 21st Century*. Washington, DC: The National Academies Press, 2002.
100. Delemos JL. Community-based participatory research: changing scientific practice from research on communities to research with and for communities. *Local Environ*. 2006;11:329–338.

Cite this article as: Ricks JM, Arthur EK, Stryker SD, Yockey RA, Anderson AM, Allensworth-Davies D (2022) A systematic literature review of community-based participatory health research with sexual and gender minority communities, *Health Equity* 6:1, 640–657, DOI: 10.1089/heq.2022.0039.

Abbreviations Used

AHRQ = Agency of Healthcare Research and Quality
AIDS = acquired immune deficiency syndrome
CBPR = community-based participatory research
GBMSM = gay, bisexual and other men who have sex with men
LGBTQ = lesbian, bisexual, transgender, queer
MSM = men who have sex with men
POC = people of color
RCTs = randomized controlled trials
SDOH = social determinants of health
SGM = sexual and gender minority
SGMY = sexual or gender minority youth
SOGIs = sexual orientation and gender identities
TGD = transgender and gender diverse
TGNC = transgender/gender non-conforming
TW = transgender women

Publish in Health Equity



- Immediate, unrestricted online access
- Rigorous peer review
- Compliance with open access mandates
- Authors retain copyright
- Highly indexed
- Targeted email marketing

liebertpub.com/heq

