

FULL-LENGTH ARTICLES

Participatory Research Emergent Recommendations for Researchers and Academic Institutions: A Rapid Scoping Review

Benjamin D Scher , Juliet Scott-Barrett , Matthew Hickman , Benjamin W Chrisinger 

Keywords: Participatory Research, Community Engagement, Participatory Methods, Rapid Scoping Review

<https://doi.org/10.35844/001c.74807>

Journal of Participatory Research MethodsVol. 4, Issue 2, 2023

In recent years, a range of academic disciplines have emphasized the potential benefits of prioritizing meaningful engagement with individuals and communities who have lived and have living experience with the topics, phenomena and problems researchers seek to study. In March 2022, we were asked to produce a paper to inform a university workshop and training materials to help students and faculty engage with participatory methods. In turn, we conducted a rapid scoping review of reviews to document key recommendations relating to methodology, logistics and ethics within the various modes of participatory research. Searches were conducted in Web of Science, SCOPUS, ProQuest, Pub Med, OVID (including Medline, PschyInfo/EMBASE, APAPsych) to identify published academic reviews (e.g., systematic, scoping, literature reviews and evidence gap maps), for best practices relating to participatory research. This approach drew out aggregated best practices and lessons learned across many primary studies and increased the speed of the review. From 276 studies imported for screening, 43 full-text studies were assessed for eligibility and 28 were deemed relevant for full inclusion. Results are presented as: 1) participatory research recommendations for researchers; and 2) participatory research recommendations for academic institutions. Three sub-themes emerged within the context of suggestions for researchers engaging with participatory methods: 1) early-stage considerations for study design and planning; 2) conducting the research; and 3) dissemination and knowledge exchange. This rapid scoping review highlights key recommendations for researchers interested in using participatory approaches in their own research, and for academic and institutional stakeholders who aim to support these practices.

1. Background, Rationale, and Relevance

There is growing evidence of the importance and value of respectful, inclusive, and collaborative participatory approaches across different disciplines (e.g., Bonello et al., 2022; Fletcher-Watson et al., 2019; Marzi, 2021; Vaughn & Jacquez, 2020; Zimmerman et al., 2019), as well as increasing recognition of the potential reach and relevance of meaningfully co-produced knowledge (Balazs & Morello-Frosch, 2013; Phillips et al., 2022; Rix et al., 2022; Vaccaro, 2020). There is a recognition that many types of research can benefit from engagement with, or leadership from, those with lived experience of the issues in focus (Marrone et al., 2022; Viswanathan et al., 2004; Wallerstein et al., 2020; Wallerstein & Duran, 2010). The quality of the research, and the potential for broader impacts and more reciprocal transformations (Marzi & Pain, 2022), can be developed through deeper collaborative engagement with non-academic partners (Balazs & Morello-Frosch, 2013; Zimmerman et al., 2019). Monitoring and addressing power differentials and sharing control with and between academic researchers and

non-academic stakeholders¹ entails ethical, logistical, and structural considerations for those engaging in participatory approaches (Duea et al., 2022; Lenette et al., 2019; Minkler et al., 2012; Resnik & Kennedy, 2010).

1.1 Conceptualising and defining meaningful participatory research

Participatory research shares many underpinning characteristics with community engagement more broadly: it must be respectful, accessible, inclusive and ethically grounded throughout (Bonello et al., 2022; Fletcher-Watson et al., 2021; Spiel et al., 2020; Wali et al., 2021). Here, we avoid a strict definition of “participatory research,” and instead make a few important distinctions which were agreed upon in consultation with university stakeholders and collaborators. First, respect, collaboration, and inclusivity must be reflected in all research processes: participatory research involves adapting, augmenting, or—in some cases—completely reconceptualising traditional ways of doing academic research to offer new or different avenues for non-academic stakeholders to participate (Blumenthal et al., 2013). Second, it often involves data collection methods familiar to qualitative researchers (i.e., individual interviews or focus groups): the use of these methods alone does not constitute participatory research but rather these methods can be a means to involve, collaborate, and share decisions with different stakeholders (Vaughn & Jacquez, 2020). Third, despite its qualitative orientation, participatory research can include other methods, including the development of statistical models or the production of systematic reviews (Jason & Glenwick, 2016; Leavy, 2017; Oyana, 2017; Vaughn & Jacquez, 2020). Finally, it can involve different or multiple research phases (i.e., design, implementation, analysis, dissemination), and to varying degrees within each stage (e.g., from community stakeholders giving feedback on the research questions to being formally included as members of the research team) (Hacker et al., 2012; Satcher, 2005). To navigate and develop more genuine participation and transparency in the process, Vaughn and Jacquez (2020) conceptualise “participation choice points,” illustrating how decisions can be made (and shared) about the degree of participation at each stage in the research process (see Vaughn & Jacquez, 2020, p. 6 for illustration).

For the purposes of this review, we do not take a normative position on how much or what kind of “participation” makes a study “participatory;” rather, we provide evidence of better practice recommendations from the many ways participatory approaches can be used in research, offering researchers a broad palette of approaches and ideas to consider in their own areas of interest. Insights from the most involved forms of participation might still help shape our imagination for using elements of participatory approaches in smaller,

¹ When discussing academic stakeholders, we are referring to individuals or groups who have a direct or indirect interest in the activities and outcomes of academic institutions (i.e., students, faculty members, administrators, funding agencies, university governing bodies and alumni). When discussing non-academic stakeholders, we are referring to individuals or groups who are not part of the academic community but have a direct or indirect interest in the research outcomes of a specific research project (i.e., specific patient and patient advocacy groups, industry partners, community groups, NGOs or government agencies implicated within a research project).

meaningful ways. Despite the broadness of what is included, we echo the important focus in the literature on the key principles that must underpin participatory processes and interactions: critical reflection, respect, meaningful engagement, reciprocal capacity building, and shared learning (Duea et al., 2022; Wallerstein, 2020). We use this review to illustrate how some of the micro-decisions and preparations have an important bearing on the process and practice of participatory approaches, and how these considerations may help researchers navigate both risks and opportunities as they emerge in the research (Lenette et al., 2019).

1.2. Research Question and Aim of this Scoping Review

In early 2022, our university began an institution-wide endeavor to provide support and training for academic staff and students interested in using participatory research methods. To start, they commissioned a review of key recommendations from the literature that could inform subsequent phases of the project and the development of training materials. This paper summarises our review efforts and findings. The primary aim of this review was to survey the published academic literature for key recommendations on participatory research practices. In particular, our charge was to summarize learnings about how to plan, deliver and evaluate high-quality participatory research activity, and also how to support and encourage a culture of participatory research within a university setting. The defined research question for this review was: “Based on available peer-reviewed published literature, what are key learnings and subsequent recommendations related to high-quality participatory research, specifically in relation to the planning, implementation, evaluation, and promotion of participatory research within academic institutions?”

Where evident in the literature, we also hoped to highlight high-quality resources that already exist (nationally and internationally) to support participatory research activities. We hope to contribute to the diverse and growing body of resources and guides detailing inclusive participatory approaches (e.g., Centre for Disability Studies, 2021; Duea et al., 2022; Minkler et al., 2012; Vaughn & Jacquez, 2020), and hope to offer a review that interweaves methodological, practical and ethical considerations to support individuals planning for and developing more meaningful and respectful participatory practices.

2. Methods

Given the broad and sometimes inconsistent definitions for what constitutes “participatory research” and the different ways this can be operationalized in different disciplines and research settings (e.g., hospitals, neighborhoods, online spaces), a scoping review was determined to be the best search approach. A *rapid* scoping review was selected to be responsive to project deadlines and deliverables, as this review is intended to inform a suite of training materials under development for University of Oxford staff, students and researchers (Tricco et al., 2015). Beyond these logistical constraints, the rapid review format allowed us to focus on studies that called themselves “participatory,”

rather than the much broader task of including studies that use approaches we might recognize as participatory, but without the self-described labeling. Furthermore, we focused our attention on published reviews, both as a strategy for drawing out aggregated best practices and lessons learned across many primary studies, and to increase the speed of the review.

2.1. Search terms and databases

We developed a preliminary set of search terms and circulated it among other researchers and a social sciences reference librarian for feedback. The term “participatory” is often used as an umbrella term to capture a multitude of more precisely defined research practices. As such, we included additional forms of research; although they do not contain the term “participatory” in their description, they are very much aligned in terms of their ethos of prioritizing meaningful engagement with both stakeholders and participants. The full list of search terms appears in Supplemental Table 1. Searches were conducted in Web of Science, SCOPUS, ProQuest, Pub Med, OVID (including Medline, PschyInfo/EMBASE, and APAPsych).

2.2. Inclusion and exclusion criteria

Inclusion and exclusion criteria fell under three categories: 1) to extract best practices across multiple fields, we included reviews or syntheses of primary studies (e.g., systematic, scoping, and literature reviews and evidence gap maps) and excluded primary studies and review protocols; 2) to extract practices that were self-aware as academic/professional research, we included participatory methods as research and excluded studies that explore participation as an outcome but not as part of the design (e.g., interventions to increase participation or interventions that user participation to increase adherence to treatment); and 3) due to the spoken languages of the researchers, we only included studies published in English and excluded studies published in other languages without English translations available. We independently assessed studies for inclusion and exclusion using Covidence [2022, v299701009352], with disagreements discussed until a consensus could be reached.

2.3. Data extraction and analysis

A data extraction table was developed to extract relevant data, including: description and rationale of best practice methodology; discipline of focus; description of the public actively involved in the participatory method; barriers to implementing the participatory method of focus; facilitating strategies; and recommendations for successful participatory research implementation. We thematically analyzed this extracted information related to best practices, using multiple rounds of theme development and definition, again seeking feedback from other researchers. This qualitative analysis approach is in line with the “codebook” version of thematic analysis described by Braun and Clarke (2021), where agreement between independent coders is sought as a process of iteration and discussion, rather than as a tool of quality assessment (e.g., inter-rater reliability scores).

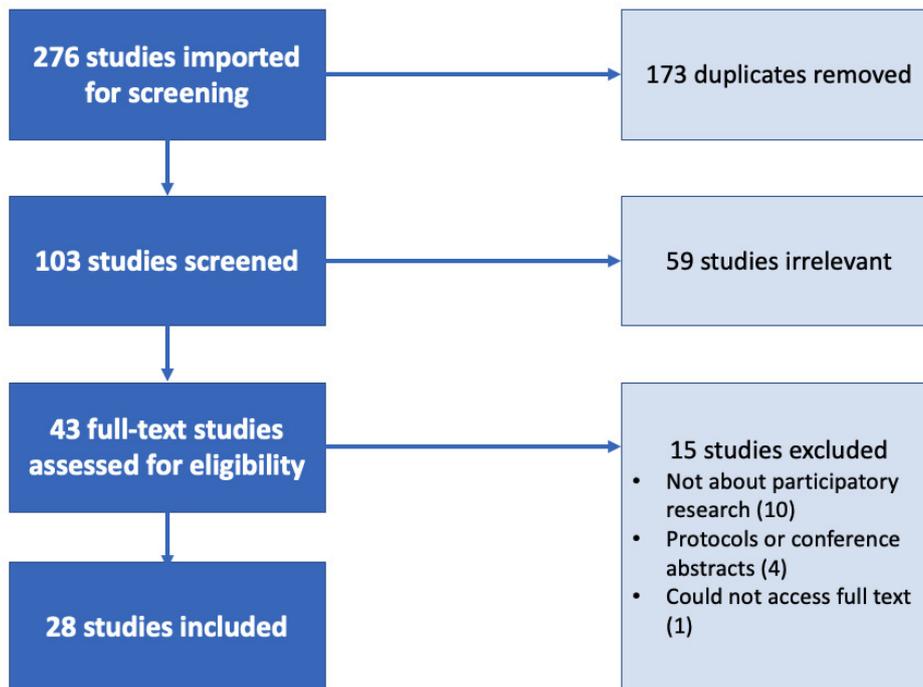


Figure 1. PRISMA flowchart for rapid scoping review

In conducting our codebook-oriented thematic analysis (Braun & Clarke, 2006), we began by familiarizing ourselves with the extracted data. Two researchers with prior participatory research experience, Scher and Chrisinger, read and re-read the data, took notes about analytic ideas, and reacted to the data (Braun & Clarke, 2021). Next, we collaboratively created a multi-level coding framework to systematically analyze the data and identify relevant and meaningful recommendations related to our research question. The coding process involved iteration and refinement until all data were either organized or excluded from consideration. The themes were developed based on important patterns of meaning across the different stages of participatory research (Braun & Clarke, 2021). As per the principles of thematic analysis, the themes were further refined and synthesized as we developed the headings for our findings and recommendations, and throughout the writing process, we synthesized them to create a cohesive set of results and recommendations. We used the final set of emergent best practice themes to summarise the rapid review findings.

3. Results

3.1. Overview of Included Studies

From 276 studies imported for screening, 173 were removed as duplicates, leaving 103 studies that underwent abstract screening. From these, 59 were deemed irrelevant, leaving 43 full-text studies which were assessed for eligibility. A further 15 studies were excluded as they were: 1) best practices not related to participatory methodology; 2) protocols or conference abstracts; or 3) inaccessible in a full-text format. Following this process, 28 studies were deemed relevant for full inclusion. [Figure 1](#) illustrates these procedures.

The self-declared methodological focus of included reviews included: community-based participatory research (n=8); public, patient or stakeholder involvement (7); participatory/creative methods broadly (5); co-research (3); image methods (2); action research (2); body-mapping (1); and mystery client (1). Of these, the self-declared demographic or disciplinary focus of studies concerning the use of the specified participatory method included Indigenous, Native American or Pacific Islander (5), patient stakeholder groups (5), age specific (2), cancer patients (2), neurodivergent groups (2), psychology studies (2), people who use drugs (1), environment health research (1), participant-generated image methods (1), organizations broadly (1), photovoice (1), body-mapping studies (1), health services in low and middle income countries (1), publics involved in genomics research (1), and action research in e-health (1). The full description of the review characteristics appears in [Table 1](#).

Below, we summarise key recommendations for researchers and academic institutions seeking to engage in participatory research based on our thematic codes and subcodes (see Supplemental Table 2). We elaborate on these recommendations in sections tailored toward researchers interested in using participatory approaches in their own research, and for academic and institutional stakeholders who aim to support these practices. In each section, we have generally organized the recommendations in order of research phase (i.e., preparation to dissemination).

Participatory Research Recommendations *for Researchers*

3.2. Early-Stage Considerations for Study Design and Planning

3.2.1. Build Relationships and Trust with Individuals and Community Stakeholder Groups

A foundational principle of participatory research is a commitment to actively building relationships and trust with individuals and stakeholder groups within the community of interest. Cowdell et al. (2022) suggest that when participating members feel valued, heard, engaged, and empowered not only are they more committed to the research process, but they also report more positive experiences in participating in research. Harrison et al. (2019) and Shen et al. (2017) advise that in order to develop trust, initiating participation with individuals and stakeholder groups should start as early as possible. Early involvement will allow for continual conversation around the intentions of the research, the study design, and the way in which the study will be conducted (Harrison et al., 2019; Shen et al., 2017).

O'Brien et al. (2021) note how recognizing and continually reflecting on dynamics related to power differentials, confidentiality, and communication will enhance the quality of relationships developed between academic researchers and community stakeholders. Accounting for power differentials has been especially critical for researchers working with Indigenous and traditionally oppressed communities, though authors highlight that when considering any community-engaged study design, researchers should still consider power dynamics in settings with less-apparent historical, economic, and social inequities (McElfish et al., 2019; Wali et al., 2021).

Table 1. Characteristics of Included Studies

Study Number	Study Title	First Author(s)	Journal	Publication Date	Type of Study	Population, Institution or Practice of Focus	Participatory Method of Focus	Self-defined Discipline
1	Involving the public in systematic reviews: a narrative review of organizational approaches and eight case examples	Boote et al.	Journal of Comparative Effectiveness Research	2012	Narrative Review	Organizations	"Involving the public in systematic review"	Health Research
2	A Review of Participant-Generated Image Methods in the Social Sciences	Balamenou & Garrod	Journal of Mixed Methods Research	2016	Systematic Review	Participant-Generated Image Method Studies	"Participant-Generated Image Methods" (auto-photography, participatory photography, photo-elicitation, photographic methods, photovoice)	Social Sciences
3	Strategies for culturally safe research with Native American communities: an integrative review	Brockie et al.	Contemporary Nurse	2021	Integrative Review	American Indian/ Native American/ Alaska Native	Community-Based Participatory Research/Consumer Driven Community-Based Research	Health, Social, and Cultural Research
4	Photovoice: A Review of the Literature in Health and Public Health	Catalani & Minkler	Health Education and Behavior	2009	Review	Photovoice Studies	Photovoice	Health and Public Health Related Research
5	A systematic review of the use of adolescent mystery clients in assessing the adolescent friendliness of health services in high-, middle-, and low-income countries	Chandra-Mouli et al.	Global Health Action	2018	Systematic Review	Health Services in High, Middle and Low-Income Countries	Mystery Clients	Health and Public Health Related Research
6	How and how well have older people been engaged in healthcare intervention design, development or delivery using co-methodologies: A scoping review with narrative summary	Cowdell et al.	Health and Social Care in the Community	2020	Scoping Review	Older People	Intervention co-design, co-development, co-delivery using co-research methodologies	Health and Health Related Research
7	Embodied Ways of Storying the Self: A Systematic Review of	De Jager et al.	Qualitative Social Research	2016	Systematic Review	Body-Mapping Studies	Body-Mapping	Medical, Health, Social

Study Number	Study Title	First Author(s)	Journal	Publication Date	Type of Study	Population, Institution or Practice of Focus	Participatory Method of Focus	Self-defined Discipline
	Body-Mapping							and Cultural Research
8	Co-research with adults with intellectual disability: A systematic review	Di Lorito et al.	Journal of Applied Research in Intellectual Disabilities	2017	Systematic Review	Adults With Intellectual Disabilities	Intervention Co-Design, Co-Development, Co-Delivery using Co-Research Methodologies	Medical, Health, Social and Cultural Research
9	The Underutilization of Community-based Participatory Research in Psychology: A Systematic Review	Espinosa & Verney	American Journal of Community Psychology	2020	Systematic Review	Psychology Studies	Community-Based Participatory Research	Psychology
10	Community-Engaged Approaches to Cervical Cancer Prevention and Control in Sub-Saharan Africa: A Scoping Review	Habila et al.	Frontiers in Global Women's Health	2021	Scoping Review	Cervical Cancer Patients	Community-Based Participatory Research	Health and Public Health Related Research
11	Patient stakeholder engagement in research: A narrative review to describe foundational principles and best practice activities	Harrison et al.	Health Expectations	2019	Narrative Review	Patient Stakeholders (patients, families and caregivers)	Patient Stakeholder Engagement	Health and Health Related Research
12	Lessons Learned from three Inquiries on Capacity	Hearod	The University of Oklahoma Health Sciences Center ProQuest Dissertations Publishing	2018	Literature Review	American Indian Communities	Community-Based Participatory Research	Medical, Health, Social and Cultural Research
13	A review of literature about involving people affected by cancer in research, policy and planning and practice	Hubbard et al.	Patient Education and Counseling	2007	Systematic Review	Cancer patients	Participatory Research Broadly	Healthcare Research
14	Best practice framework for Patient and Public Involvement (PPI) in collaborative data analysis of qualitative mental health research: methodology development and refinement	Jennings et al.	BMC Psychiatry	2018	Critical Literature Review	Patients and the Public	Patient and Public Involvement (PPI) in collaborative data analysis of qualitative mental health research	Mental Health and Related Research

Study Number	Study Title	First Author(s)	Journal	Publication Date	Type of Study	Population, Institution or Practice of Focus	Participatory Method of Focus	Self-defined Discipline
15	Assessing the influence of researcher-partner involvement on the process and outcomes of participatory research in autism spectrum disorder and neurodevelopmental disorders: A scoping review	Jivraj et al.	Autism	2014	Scoping Review	Autistic individuals and individuals with other neurodevelopmental conditions	Participatory Research Broadly	Health and Health Related Research
16	A scoping review: The utility of participatory research approaches in psychology	Levac et al.	Journal of Community Psychology	2019	Scoping Review	Psychology Research	Participatory Research Broadly	Psychology Research
17	Best Practices for Community-Engaged Research with Pacific Islander Communities in the US and USAPI: A Scoping Review	McElfish et al.	Journal of Health Care for the Poor and Underserved	2019	Scoping Review	Pacific Islander Communities in the US and US Affiliated Pacific Islands	Community-Engaged Research Broadly	Medical, Health, Social and Cultural Research
18	Participatory Methods to Engage Health Service Users in the Development of Electronic Health Resources: Systematic Review	Moore et al.	Journal of Participatory Medicine	2019	Systematic Review	Health Service Users	Participatory Methods Broadly in the development of electronic health resources	Health and E-Health Related Research
19	Public Involvement in Global Genomics Research: A Scoping Review	Nunn et al.	Frontiers in Public Health	2019	Systematic Review	Publics Involved in Genomics Research	Public Involvement	Human Genomics Research
20	Best Practices and Lessons Learned for Action Research in eHealth Design and Implementation: Literature Review	Oberschmidt et al.	Journal of Medical Internet Research	2022	Literature Review	Action Research in eHealth Design and Implementation	Action Research	Health and E-Health Related Research
21	A scoping review of the use of co-design methods with culturally and linguistically diverse communities to improve or adapt mental health services	O'Brien et al.	Health and Social Care in the Community	2021	Scoping Review	Culturally and Linguistically Diverse (CALD) communities Engaging with Mental Health Services	Co-Design Methods Broadly	Health and Mental Health and Related Research
22	The ethics of community-based research with people who use drugs: results of a scoping review	Souleymanov et al.	BMC Medical Ethics	2016	Scoping Review	People Who Use Drugs	Community-Based Participatory Research	All Community-Based Research

Study Number	Study Title	First Author(s)	Journal	Publication Date	Type of Study	Population, Institution or Practice of Focus	Participatory Method of Focus	Self-defined Discipline
23	How and why should we engage parents as co-researchers in health research? A scoping review of current practices	Shen et al.	Health Expectations	2016	Scoping Review	Parents	Co-Research and Patient Engagement Broadly	Health, Medical and Public Health Related Research
24	Patient and service user engagement in research: a systematic review and synthesized framework	Shippee et al.	Health Expectations	2013	Systematic Review	Patients and Service Users	Patients and Service User Engagement Broadly	Biomedical and Health Related Research
25	Co-production practice and future research priorities in United Kingdom-funded applied health research: a scoping review	Smith et al.	Health Research Policy and Systems	2022	Scoping Review	Healthcare Patients in the UK	Co-Production in Healthcare Services and Research Broadly	Health and Related Research
26	Using Participatory and Creative Methods to Research Gender-Based Violence in the Global South and With Indigenous Communities: Findings From a Scoping Review	Thomas et al.	Trauma, Violence and Abuse	2020	Scoping Review	Indigenous Communities in the Global South	Participatory and Creative Methods Broadly	Medical, Health, Social and Cultural Research
27	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	Wali et al.	International Journal of Equity in Health	2021	Scoping Review	Indigenous Populations in North America	Community-Engaged Research Broadly	Health and Health Related Research
28	Key Components of Collaborative Research in the Context of Environmental Health: A Scoping Review	Wine et al.	Journal of Research Practice	2017	Scoping Review	Environmental Health Related Collaborative Studies	Co-Creation/Co-Production Broadly	Environmental Health Related Research

3.2.2. Engage Community Members Throughout the Research Process

Participatory approaches to research emphasize the importance of engaging community members throughout the research process (Cowdell et al., 2022; Nunn et al., 2019; O'Brien et al., 2021). Advisory groups comprised of both academic and community members can facilitate this collaboration and ensure community-defined concerns direct the trajectory of research (Brockie et al., 2021; Di Lorito et al., 2018; Harrison et al., 2019; Levac et al., 2019; Wali et al., 2021). To address power inequalities and promote inclusivity, it is important to include people with lived and living experience of the issues under study as members of the research team (Jennings et al., 2018; Levac et al., 2019; O'Brien et al., 2021; Shippee et al., 2015). When recruiting community co-researchers and advisory group members, it is valuable to partner with community organizations that have important knowledge and expertise (Levac et al., 2019). Additionally, conducting an Equality Impact Assessment and having open discussions about language can help avoid entrenching existing inequalities or producing unintended outcomes (Jennings et al., 2018; Levac et al., 2019; Wali et al., 2021). Lastly, obtaining final study approval from the community advisory group can ensure that any overlooked or new issues have been accounted for (Levac et al., 2019; Wali et al., 2021).

3.2.3. Employ a Collaborative Approach in the Design of Ethical Protocols

Participatory research has often been conducted with communities who have historically been oppressed or excluded from participating in research processes (Moore et al., 2019; O'Brien et al., 2021; Thomas et al., 2022). As a result, many of these communities have developed their own ethical guidelines and research protocols for researchers to consult and abide by when initiating and conducting participatory research (see Supplemental Table 3 for examples). Identified authors all recommend scoping for internationally relevant protocols before the research process to ensure that a project, from its earliest forms of engagement, is responsive to local contexts (Brockie et al., 2021; Jivraj et al., 2014; McElfish et al., 2019; Moore et al., 2019; Scheim et al., 2015; Shen et al., 2017; Thomas et al., 2022; Wali et al., 2021). Reporting engagement with established protocols will also ensure the transparency and validity of methods used and will further refine and improve on best practice standards within these protocols.

After gaining an understanding of appropriate international protocols, it is recommended that researchers gather input from community partners (e.g.: tribal/community advisory boards, project advisory group) to confirm the applicability of the study design and amend where necessary in light of appropriate ethical and/or procedural protocols (Jivraj et al., 2014; O'Brien et al., 2021). This will work to ensure culturally safe research methods and engagement practices that are inclusive of the partners' perspectives (Brockie et al., 2021). Researchers should ensure the chosen, adapted, or developed ethical protocol balances risks and benefits to communities and individuals and these should be clearly considered and communicated to participants (Scheim

et al., 2015). Finally, where appropriate, researchers should seek ethical review from tribal Institutional Review Boards in relation to chosen, amended, or developed protocols, even though it may not be part of funding requirements (Brockie et al., 2021).

3.2.4. Seek to Understand Cultural Context and Respect Cultural Norms

Due to differences in culture and the ways that communities operate, conventional approaches to co-design may need to be reconsidered and adapted to fit the particular community context (O'Brien et al., 2021). Best practice recommendations assert the importance of researchers seeking to understand their specific cultural context of focus and in particular appreciate if and how historical injustices (e.g., colonialism) bear upon present circumstances (e.g., structural racism, marginalization) (Brockie et al., 2021; Habila et al., 2021; Levac et al., 2019; McElfish et al., 2019; O'Brien et al., 2021; Thomas et al., 2022). These dynamics can influence trust and power dynamics between community members and research teams (Brockie et al., 2021; O'Brien et al., 2021). These authors advocate that research practices not only appreciate the realities of historical structural inequalities but actively work to address them by respecting, familiarizing, and engaging with cultural norms during the research design phase.

Habila et al. (2021) propose the additional strategy of working with language interpreters (if needed), cultural advisors, or existing community leaders to identify key areas of research interest and best practices for collecting and using information and selecting appropriate underpinning theoretical research frames, all to be considered in the research design. Authors also note that in research with Indigenous groups, community partners may also be able to advise on ways to utilize community/tribal governance procedures that promote cultural safety, respect collectivist cultural structures, and work to mitigate any potential stigmatizing outcomes of participating in research (Brockie et al., 2021; McElfish et al., 2019).

3.2.5. Build Capacity for Participation in the Community of Interest

Research capacity within the community of interest can be built using low-threshold and flexible training to teach basic principles and theoretical understandings about the methodology being used (Schein et al., 2015). This can lead to more appropriate research topics and processes, more success with recruitment, and a bridged knowledge-to-action gap (Brockie et al., 2021; Catalani & Minkler, 2010; Chandra-Mouli et al., 2018; Di Lorito et al., 2018; Habila et al., 2021; Harrison et al., 2019; Hawke et al., 2020; Hubbard et al., 2007; Jennings et al., 2018; McElfish et al., 2019; Oberschmidt et al., 2022; Schein et al., 2015; Shen et al., 2017; Shippee et al., 2015). Further, warm-up and reflective exercises can orient community members to the research processes and tasks at hand and create a more inviting atmosphere for participation (Schein et al., 2015).

Involving community members from the outset of decision-making will also help to build capacity and a greater understanding of research principles (McElfish et al., 2019). Certain communities may be well accustomed to engaging and participating in research. In such cases, training may not be necessary or may be completely community-led. Brockie et al. (2021) and Shippee et al. (2015) both discuss this process, highlighting that training may need to be initiated by the researcher and then delivered in consultation with community leaders. These authors also highlight that this training and initial research engagement should be seen and designed as a platform through which to develop leadership capacity with the goal of transitioning traditional research leadership from academia to the community of focus.

3.3. Conducting the Research

3.3.1. Provide Varied and Flexible Avenues for Participation

When working with community groups, it is important for researchers to provide multiple avenues for engagement and participation as well as be open to flexible and adaptive research processes (Jennings et al., 2018; McElfish et al., 2019; O'Brien et al., 2021; Scheim et al., 2015; Shen et al., 2017; Shippee et al., 2015; Wali et al., 2021). For certain groups (e.g., parents with young children or unhoused individuals) it is important to use flexible and accommodating methodologies that both align with research aims and are responsive to the social realities of co-researchers and participants (Jennings et al., 2018; Scheim et al., 2015; Shen et al., 2017). This will ensure that individuals are not entirely excluded from study involvement if they are deemed (or deem themselves) unable to participate in the study at a particular time (Scheim et al., 2015).

Finally, to facilitate the development and implementation of such methodologies, the researcher should provide details to the community regarding various modes of community engagement (McElfish et al., 2019; Wali et al., 2021). This will allow the community to approve the appropriate methods or propose alternatives that are contextually appropriate.

3.3.2. Involve Community Members in Data Collection

A variety of best practices were identified for involving community members in aspects of data collection and analysis. Harrison et al. (2019) recommend that, where possible, researchers hire auxiliary staff who are from the community as they will have an in-depth knowledge of the local context, partners, and local systems. Further, authors encourage researchers to include community members in the conduct of interviews and/or the recruitment of participants through agreed-upon terms of purposive or snowball sampling within their social networks (Habiba et al., 2021; Scheim et al., 2015; Wali et al., 2021). A review of participatory studies engaging networks of people who use drugs conducted by Scheim et al. (2015) demonstrated that peer recruitment was integral to recruiting large and diverse samples. However, this method also presented ethical challenges regarding support for recruiters, coercive recruitment, and participant confidentiality. Within these collaborations it is imperative that involved community members are treated as

Table 2. Early-Stage Considerations for Study Design and Planning

Recommendation	Key Points	Citations
3.2.1. Build Relationships and Trust with Individuals and Community Stakeholder Groups	<ol style="list-style-type: none"> 1. Actively build relationships and trust with individuals and stakeholder groups within the community. 2. Initiate participation with individuals and stakeholder groups as early as possible. 3. Recognize and reflect on dynamics related to power differentials, confidentiality, and communication. 	Cowdell et al. (2022); Harrison et al. (2019); McElfish et al. (2019); O'Brien et al. (2021); Shen et al. (2017); Wali et al. (2021)
3.2.2. Engage Community Members Throughout the Research Process	<ol style="list-style-type: none"> 1. Engage community members throughout the research process. 2. Use advisory groups comprised of both academic and community members to facilitate collaboration. 3. Include people with lived and living experience as members of the research team. 4. Partner with community organizations to recruit community co-researchers and advisory group members. 5. Conduct an Equality Impact Assessment and have open discussions about language. 6. Obtain final study approval from the community advisory group. 	Brockie et al. (2021); Cowdell et al. (2022); Di Lorito et al. (2018); Jennings et al. (2018); Levac et al. (2019); Nunn et al. (2019); O'Brien et al. (2021); Shippee et al. (2015); Wali et al. (2022)
3.2.3. Employ a Collaborative Approach in the Design of Ethical Protocols	<ol style="list-style-type: none"> 1. Scope for internationally relevant protocols before the research process to ensure responsiveness to local contexts. 2. Gather input from community partners to confirm the applicability and amend where necessary appropriate ethical and/or procedural protocols. 3. Ensure the chosen, adapted or developed ethical protocol balances risks and benefits to communities and individuals and that these are clearly considered and communicated to participants. 4. Seek ethical review from tribal Institutional Review Boards where appropriate. 	Brockie et al. (2021); Jivraj et al. (2014); McElfish et al. (2019); Moore et al. (2019); O'Brien et al. (2021); Scheim et al. (2015); Shen et al. (2017); Thomas et al. (2022)
3.2.4. Seek to Understand Cultural Context and Respect Cultural Norms	<ol style="list-style-type: none"> 1. Reconsider and adapt conventional approaches to co-design to fit the community context. 2. Understand cultural context and respect cultural norms. 	McElfish et al. (2019); O'Brien et al. (2019); Tait et al. (2018); Thomas et al. (2022)
3.2.5. Build Capacity for Participation in the Community of Interest	<ol style="list-style-type: none"> 1. Provide low-threshold and flexible training to build research capacity within the community of interest 2. Utilize warm-up and reflexive exercises during these training sessions 3. Training may need to be initiated by the researcher and delivered in collaboration or by community leaders 	Brockie et al. (2021); Catalani & Minkler (2010); Chandra-Mouli et al. (2018); Di Lorito et al. (2018); Habila et al. (2021); Harrison et al. (2019); Hawke et al. (2020); Hubbard et al. (2007); Jennings et al. (2018); McElfish et al. (2019); Oberschmidt et al. (2022); Scheim et al. (2015); Shen et al. (2017); Shippee et al. (2015)

equals (Cowdell et al., 2022; Shen et al., 2017; Shippee et al., 2015). Cowdell et al. (2022) specify examples such as recognition and encouragement of participants/community advisory group contributions, as well as practical actions such as collaborative brainstorming, when problems arise within the research.

3.3.3. Consider If and How to Compensate Participants

Researchers should explore compensation best practices with regards to the specific demographic being worked with (e.g., ethical setting of compensation amounts and type)² (Scheim et al., 2015). This should be considered from the outset of research design and incorporated appropriately into funding applications. Authors highlight the benefits of clearly communicating with communities and potential participants about compensation (Scheim et al., 2015; Thomas et al., 2022). Further, to ensure safety of both participants and researchers, researchers should monitor for unintended harms related to compensation in the research process and report incidents to relevant stakeholders and ethical review bodies (Thomas et al., 2022).

3.3.4. Anticipate Flexible Timelines

Numerous authors state the importance of planning for longer time horizons than might be necessary for other less-participatory kinds of research, as well as the ability to adjust timescales and processes as the project progresses (Boote et al., 2012; Cowdell et al., 2022; Hubbard et al., 2007; Moore et al., 2019; Shen et al., 2017). Boote et al. (2012) and Moore et al. (2019) suggest that this kind of “patient” research may mean that participatory projects take longer, and thus may not always be suited to certain kinds of time-sensitive research (e.g., those studying rapidly changing technologies or demanding time-pressured policy recommendations). Additionally, in the study design, researchers should anticipate some unpredictability: have backup plans and conflict resolution strategies, make the research process transparent, and ensure participants are aware of everything from the start — including the inherent unpredictability of research (Shen et al., 2017).

3.3.5. Consider Special Budgetary Needs

Participatory projects may require different or additional budget items than more traditional projects and equitable compensation for project partners and participants is a critical consideration (Cowdell et al., 2022; Harrison et al., 2019; Hubbard et al., 2007; Jennings et al., 2018; Shen et al., 2017). These reviews caution that such budget items may take the form of payments to account for staff time (for partner organizations), foregone wages (for participants who may have to choose between work and participating), or other direct payments to participants in recognition of their contributions.

² Example of compensation best practice review: Greer, A. M., Pauly, B., Scott, A., Martin, R., Burmeister, C., & Buxton, J. (2019). Paying people who use illicit substances or ‘peers’ participating in community-based work: a narrative review of the literature. *Drugs: education, prevention and policy*, 26(6), 447–459.

Additionally, the costs of ensuring transparency and access to project processes and outcomes should also be considered, such as high-quality project websites or open-access publication fees. Other budget items may help offset the costs of participation (e.g., offering reimbursements for transport, providing refreshments or childcare). The above reviews all recommend that questions of “What is fair and ethical compensation?” should be discussed in the early planning phases of a project, so that appropriate budgets can be secured and the agreed compensation is delivered throughout the project (Hubbard et al., 2007).

3.3.6. Leverage Staff and Structural Supports

Those utilizing a participatory approach should support both co-researchers from the community and participants by considering structural supports (Hubbard et al., 2007; Jennings et al., 2018; Shen et al., 2017; Wine et al., 2017). For instance, it may be helpful to include staff with the right kinds of skills to enable participation, experience facilitating group discussions, and/or conducting data analysis with community members. It may also be useful to consider removing barriers to language by offering community members the option of conducting data analysis in either English or appropriate Indigenous/local languages, as well as using visual materials to make research processes accessible (Di Lorito et al., 2018; Wali et al., 2021).

Other structural supports, including meeting in convenient places, offering monetary incentives or reimbursements (as described above), allowing adequate break times, providing food and childcare, and creating group guidelines and expectations, may also be beneficial (Shen et al., 2017). Additionally, thinking about accessibility to research resources and materials is a general best practice throughout the various forms of community-based participatory research and can help ensure that diverse perspectives are able to be included (Cowdell et al., 2022).

3.3.7. Maintain Clear Communication, Expectations, and Feedback

Goals, expectations, and potential impact of participative research should be clearly communicated to all from the outset of the project and ensure that each participant is able to articulate the value of the endeavor (Cowdell et al., 2022). This includes clarification of roles within the research team, and the expected research processes and procedures (Harrison et al., 2019; Jennings et al., 2018; Oberschmidt et al., 2022; Shen et al., 2017). In relation to research team communications, regular face-to-face meetings, the appointment of an engagement coordinator, the use of lay language, neutral facilitators, accessible meetings, work in small groups, and multiple meeting modalities are all seen as best practices that facilitate successful participative research (Harrison et al., 2019). Authors also note the value of networking among community stakeholders and encourage researchers to build these opportunities into plans for regular communication and discussion (Brockie et al., 2021; Harrison et al., 2019).

3.3.8. Ensure Shared Decision-Making and Reflexivity

A review by Harrison et al. (2019) pointed to the role of shared decision-making and ownership, flexibility, and institutional support as a means of promoting a sense of equal participation. Moving through the various stages of research, Jennings et al. (2018) recommend having systematic reflective and evaluative processes to examine ongoing methods and experiences of community co-researchers involved in the project. Wali et al. (2021) advise that for ongoing consultation with the wider community, it can be useful to create interim reports that are distributed and allow for feedback before the completion of any final report.

Authors highlight the need for ongoing self-reflection and evaluation (Brockie et al., 2021; Cowdell et al., 2022; Harrison et al., 2019; Jennings et al., 2018; Levac et al., 2019; Nunn et al., 2019; Oberschmidt et al., 2022; Shippee et al., 2015; Thomas et al., 2022; Wali et al., 2021). In practice, they suggest that researchers establish open and iterative processes of discussion among researchers and community participants that are regular and clear throughout the research process. They continue to clarify that this can help identify facilitators and barriers to the ongoing research and reflect a continuing commitment to co-equal partnership with community members (Levac et al., 2019; Shippee et al., 2015; Wali et al., 2021).

3.4. Dissemination and Knowledge Exchange

3.4.1. Ensure Appropriate Reporting of Research Designs and Procedures in Publications

It is important to identify a variety of quality standards for reporting (Balomenou & Garrod, 2016; Boote et al., 2012; Brockie et al., 2021; Cowdell et al., 2022; Moore et al., 2019; Oberschmidt et al., 2022; Smith et al., 2022). This supports validity and transparency and strengthens the output of participatory research (e.g., Staniskewska et al., 2011³). These authors encourage researchers to explore whether guidelines have been published in their own field or might be adapted from similar settings. In academic publications resulting from participatory projects, ownership agreements and detailed descriptions of community-engagement processes should be delineated to ensure both transparency and replicability within future research (Boote et al., 2012). Further, when describing the community-engagement process, it's recommended that researchers detail the activities they undertake as part of co-production (e.g., which stakeholders were involved in this process and in what way ways, with a particular emphasis on how power is shared between stakeholders), record the stages of the research and implementation process that the stakeholders were involved in, record the skills that were

³ Staniskewska et al. (2011). The GRIPP checklist: Strengthening the quality of patient and public involvement reporting in research. <https://doi.org/10.1017/S0266462311000481>

Table 3. Recommendations for conducting research

Recommendation	Key Points	Citations
3.3.1. Provide Varied and Flexible Avenues for Participation	<ol style="list-style-type: none"> 1. Researchers should provide multiple avenues for engagement and participation and be open to flexible and adaptive research processes. 2. Researchers should use flexible and accommodating methodologies that align with research aims and are responsive to the social realities of co-researchers and participants. 	Jennings et al. (2018); McElfish et al. (2019); O'Brien et al. (2021); Scheim et al. (2015); Shen et al. (2017); Shippee et al. (2015); Wali et al. (2021)
3.3.2. Involve Community Members in Data Collection	<ol style="list-style-type: none"> 1. Researchers should involve community members in aspects of data collection and analysis. 2. Researchers should hire auxiliary staff from the community when possible, include community members in the conduct of interviews, and/or recruit participants through agreed-upon terms of purposive or snowball sampling within their social networks. 	Cowdell et al. (2022); Habila et al. (2021); Scheim et al. (2015), Shen et al. (2017); Shippee et al. (2015); Wali et al. (2021)
3.3.3. Consider If and How to Compensate Participants	<ol style="list-style-type: none"> 1. Researchers should explore compensation best practices for the specific demographic they will be working with. 2. Compensation should be considered from the outset of research design and incorporated appropriately into funding applications. 3. Researchers should clearly communicate with communities and potential participants about compensation. 4. Researchers should monitor for harms in the research process and report incidents to relevant stakeholders and ethical review bodies. 	Scheim et al. (2015); Thomas et al. (2022)
3.3.4. Anticipate Flexible Timelines	<ol style="list-style-type: none"> 1. Researchers should plan for longer time horizons than might be necessary in other less-participatory kinds of research and the ability to adjust timescales and processes as the project progresses. 2. Researchers should anticipate unpredictability, have backup plans and conflict resolution strategies, make the research process transparent, and ensure participants are aware of everything from the start, including the inherent unpredictability of research. 	Boote et al. (2012); Cowdell et al. (2022); Hubbard et al. (2007); Moore et al. (2019); Shen et al. (2017)
3.3.5. Consider Special Budgetary Needs	<ol style="list-style-type: none"> 1. Equitable compensation for project partners and participants is a critical consideration. 2. Budget items may take the form of payments to account for staff time (for partner organizations), foregone wages (for participants who may have to choose between work and participating), or other direct payments to participants in recognition of their contributions. 3. Costs of ensuring transparency and access to project processes and outcomes should also be considered. 4. Questions of fair and ethical compensation should be discussed in early planning phases of a project. 	Cowdell et al. (2022); Harrison et al. (2019); Hubbard et al. (2007); Jennings et al. (2018); Shen et al. (2017)
3.3.6. Leverage Staff and Structural Supports	<ol style="list-style-type: none"> 1. Include staff with skills in facilitating group discussions and data analysis with community members. 2. Offer language options and use visual materials to make research processes accessible. 3. Meet in convenient places. 4. Offer monetary incentives, reimbursements and adequate break times. 5. Provide food and childcare. 6. Create group guidelines and expectations. 7. Ensure accessibility to research resources and materials. 	Cowdell et al. (2022); Di Lorito et al. (2018); Hubbard et al. (2007); Jennings et al. (2018); Shen et al. (2017); Wali et al. (2021); Wine et al. (2017)
3.3.7. Maintain Clear Communication, Expectations and Feedback	<ol style="list-style-type: none"> 1. Regular face-to-face meetings. 2. Appoint engagement coordinator. 3. Use lay language and neutral facilitator. 4. Ensure accessible meetings and work in small groups. 5. Use multiple meeting modalities. 	Brockie et al. (2021); Cowdell et al. (2022); Harrison et al. (2019); Jennings et al. (2018); Oberschmidt et al. (2022); Shen et al. (2017)

Recommendation	Key Points	Citations
	<ol style="list-style-type: none"> 6. Build networking opportunities among community stakeholders. 7. Ensure all involved can articulate the value of the research. 	
3.3.8. Ensure Shared Decision-Making and Reflexivity	<ol style="list-style-type: none"> 1. Encourage shared decision making and ownership, flexibility, and institutional support. 2. Reflect on facilitators and barriers to ongoing research. 3. Show continuing commitment to co-equal partnership with community members. 	Brockie et al. (2021); Cowdell et al. (2022); Harrison et al. (2019, p. 2022); Jennings et al. (2018); Levac et al. (2019); Nunn et al. (2019); Oberschmidt et al. (2022); Shippee et al. (2015); Thomas et al. (2022); Wali et al. (2021)

developed by participants (including researchers), and specify the desired and achieved outcomes of these activities and the methods used to assess these outcomes (Smith et al., 2022).

3.4.2. Include Community Members in Dissemination

A number of authors recommend that participants and co-researchers be given the opportunity to be involved in research dissemination through co-authorship in project outputs (Catalani & Minkler, 2010; Di Lorito et al., 2018; Habila et al., 2021; Jennings et al., 2018). Additionally, authors note that it may be appropriate to organize a stakeholder event which would allow everyone involved in the project, including co-researchers, to disseminate findings to policymakers and community stakeholders (Catalani & Minkler, 2010; Di Lorito et al., 2018; Habila et al., 2021) They suggest that further training (e.g., presentation development, public speaking, advocacy) may be necessary to allow full participation in these dissemination phase activities.

In the knowledge exchange process and translation of participatory research projects, researchers must seek ways to balance their academic objectives with the desired outputs from community members and other various target audiences (Oberschmidt et al., 2022; Wine et al., 2017). As an example, for each target audience, researchers should seek to find ways to narrate the research in such a way that is appropriate and that others can learn from (Oberschmidt et al., 2022).

Participatory Research Recommendations for Academic Institutions

Academic institutions looking to promote participatory research need to ensure they provide researchers with appropriate training on these approaches (Espinosa & Verney, 2021; Harrison et al., 2019; Shippee et al., 2015; Wine et al., 2017). Shippee et al. (2015) recommend that this training should educate researchers on the realities of the social dynamics and relationships they will need to foster with community partners. It should also address protocols and best practices by which to measure and disseminate the results of participatory methods.

Brockie et al. (2021) suggest that some sources of grant funding and university policies may prohibit expenditures on food or payments to community members. Thus, it's necessary to procure additional funding or additional flexibility in funding and an appreciation that research that employs participatory methods is often more complex than traditional research.

Table 4. Recommendations for research dissemination

Recommendation	Key Points	Citations
3.4.1 Ensure Appropriate Reporting of Research Designs and Procedures in Publications	<ol style="list-style-type: none"> 1. Explore quality standards for reporting in the field. 2. Delineate ownership agreements and community-engagement processes in academic publications. 3. Detail activities undertaken during co-production, record skills developed by participants, and specify desired and achieved outcomes. 	Balomenou & Garrod (2016); Boote et al. (2012); Brockie et al. (2021); Cowdell et al. (2022); Moore et al. (2019); Oberschmidt et al. (2022); Smith et al. (2022)
3.4.2 Include Community Members in Dissemination	<ol style="list-style-type: none"> 1. Offer co-authorship to participants and co-researchers in project outputs. 2. Organize stakeholder events for community-based projects to disseminate findings to policymakers and community stakeholders. 3. Provide further training to enable full participation in dissemination activities. 4. Balance academic objectives with desired outputs from community members and target audiences. 	Catalani & Minkler (2010); Di Lorito et al. (2018); Habila et al. (2021); Jennings et al. (2018); Oberschmidt et al. (2022); Wine et al. (2017)

Additionally, other challenges can arise with ethical review boards, which may not be willing to accept certain degrees of ambiguity or flexibility that highly participatory projects might envisage (Brockie et al., 2021; Espinosa & Verney, 2021; McElfish et al., 2019). In response, they propose that academic institutions can further support researchers with pools of flexible funding for participatory research, and specialized training for ethical review staff who may be less familiar with the risks and benefits of participatory approaches.

At a structural level, institutions must recognize they need to change values and attitudes toward participatory methods; the authors explain this shift will require institutions to not only promote and reward the application of participatory methods but also change internal attitudes away from paternalism toward partnerships with communities (Brockie et al., 2021; Espinosa & Verney, 2021; Hubbard et al., 2007). Finally, Espinosa and Varney (2021) caution that a lack of diversity among researchers may contribute to community mistrust, affecting participation and the development of meaningful research partnerships; increasing recruitment and retention of diverse researchers and graduate students are key in this regard.

4. Discussion

The findings of this review are consistent with practical and ethical recommendations from prominent single study or single method reviews of participatory approaches (Armstrong et al., 2011; Guta et al., 2010; Wilson et al., 2018). Recommendations were identified in relation to all stages of the research process, from study design to research dissemination as well as from the broad spectrum of studies “participatory.” At their core, these recommendations outline approaches to participatory research that builds trust with communities, democratizes the production of knowledge through collaboration, and, in many cases, seeks to address, minimize, or reverse power differentials in traditionally problematic research relationships. This review

Table 5. Recommendations for academic institutions

Recommendations	Key Points	Citations
Participatory Research Recommendations for Academic Institutions	<ol style="list-style-type: none"> 1. Provide researchers with appropriate training on participatory research approaches. 2. Provide additional funding or flexibility in funding for research that employs participatory methods. 3. Provide specialized training for ethical review staff who may be less familiar with the risks and benefits of participatory research. 4. Promote and reward the application of participatory methods and change internal attitudes away from paternalism towards partnerships with communities. 5. Increase recruitment and retention of diverse researchers and graduate students. 	Brockie et al. (2021); Espinosa & Verney (2021); Harrison et al. (2019); Hubbard et al. (2007); McElfish et al. (2019); Shippee et al. (2015); Wine et al. (2017)

has highlighted the various ethical, logistical, and structural considerations that need to be built into participatory study designs from the outset. We recognize that these considerations often interrelate — for example, logistical and structural preparations are often needed to ensure there is the flexibility to be responsive when ethical dilemmas arise (equally, structures and logistics can often present barriers when navigating ethical dilemmas). Therefore, we discuss these three domains of consideration and locate the discussion in current debates in this journal and the literature more broadly, while recognizing that all three strands of consideration are essential to developing respectful, collaborative, and meaningful participation.

4.1 Ethical Considerations

To summarize how we conceptualize ethical considerations, we highlight the importance of cultural safety (Lenette, 2022), processes that reflect and respect the values, interests, and choices of all those involved (Brown, 2021), as well as recognizing the physical or emotional risks that involvement may entail (Jumarali et al., 2021). We also emphasize that ethical considerations would ideally be negotiated and co-created with the communities involved; see, for example, the Manifesto for Ethical Research in the Downtown Eastside (Boilevin et al., 2018).

We wish to highlight the continuous dialogue and self-reflexivity (Duea et al., 2022) necessary to enable researchers to navigate both ethics in practice (Guillemin & Gillam, 2004; Lenette et al., 2019; Spiel et al., 2020) and impact-in-process (Marzi & Pain, 2022). Moment-to-moment micro-decisions can: affect present and future interactions between both individuals and community partners (Wali et al., 2021); catalyze, impede, or exclude the participation of different individuals (Phillips et al., 2022); and have a huge bearing on the outcomes and impacts of the research (Derrick et al., 2018; Marzi & Pain, 2022). A helpful description of ethics in practice is explained by Lenette and colleagues (2019): “Frequently, we are navigating shifting — and competing — opportunities, risks and agendas, with ramifications both for the research and for collaborators” (p.166). Their important and honest account

emphasizes that navigating these shifts can be both physically and emotionally draining and risky (especially where their own values or identities intersect with the research focus; see also Caldera et al., 2020; Phillips et al., 2022).

This review emphasizes the significance of ethical considerations by providing context on the distinguishing features of participatory practices, which intentionally draws attention to power differentials within research encounters (Gast et al., 2022; Lenette et al., 2019), in academia (Brown & Leigh, 2018; Caldera, 2020), and in society more broadly (Nind et al., 2017). We highlight the importance of recognising and addressing racism, ableism, and other factors precipitating inequity and power hierarchies (Minkler et al., 2012; Wallerstein, 2020, p. 1), and emphasise the value of articles that specifically support researchers to develop practices that recognise and prioritise the importance of cultural safety (Lenette, 2022), and identify the role research epistemologies and methodologies have in racial justice (Rizvi, 2022a, 2022b). We draw attention to recent valuable work on how to address racism in real-time, whether in interviews (Gast et al., 2022), or when raised in discussion leveraging creative and visual approaches (Moses, 2022). We also highlight the importance of research that is explicit about the diverse expertise and experience different individuals offer, and the importance of guidance on developing research that is respectful of difference and reflects this respect in all elements of the process, from language choice and accessible co-design through dissemination practices and authorship decisions (e.g., Bonello et al., 2022; Fletcher-Watson et al., 2019; Phillips et al., 2022).

4.2 Logistical Considerations

To summarize how we conceptualize logistical considerations, we highlight the importance of access to resources and resource redistribution (especially in relation to money, time, and energy), we highlight the importance of considering location and space (ensuring spaces are accessible, welcoming, and safe), and that thoughtful preparation and support is offered (transport to and from research location, and materials for before, during, and after the research encounters). We also emphasize the value of frank conversations with co-researchers, communities, and advisory groups about feasibility, including what elements are practically possible as well as meaningful in the available timeframe (see Le Cunff et al., 2023, for helpful discussion of the value of meaningful collaboration with a community advisory group).

This process requires building trust and often entails a higher level of researcher engagement than traditional, less participatory projects (Oberschmidt et al., 2022). As demonstrated by a common focus on power differentials within the studies included in this review, participatory research is often oriented toward communities who have previously been marginalized or exploited through research practices: this has logistical implications. As such, the ideological rationale is distinctly predicated on equitable and sustainable outcomes which are not only valued by the partnering community but also framed explicitly towards informing community development or progressive social change (Armstrong et al., 2011). With this ethos of close and constant

collaboration in mind, this review shines a light on how participatory research should be a reciprocal, progressive endeavor in which each stage informs the next through systematic feedback loops.

4.3 Structural Considerations

To summarize how we conceptualize structural considerations, we highlight the work of Muller-Schoof and colleagues (2023) who provide a helpful description of how structural considerations were navigated throughout their research: structural considerations could be university processes or policies, or could be the processes or policies of the organizations involved (such as health organizations and employment protocols).

Important experiential knowledge and expertise is often not affiliated with academic institutions and organizations: including people with direct lived experience as co-researchers or advisory team members will not only improve relations between the research team and the participant group but will also increase the applicability and integrity of the research. By exploring key recommendations for academic institutions, this review has also proposed ways for universities to champion the above sentiment. The findings of this review encourage institutions to consider structural supports as equally providing support to researchers and removing barriers for participants and co-researchers. Where applicable, this increased holistic structural support has the potential to transform the historically problematic community-researcher relationship and mitigate the reproduction of damaging engagement relationships between communities and academic institutions. The aim of this review was to collate and outline how researchers and institutions can implement participatory research practices that benefit partnering communities.

This review has highlighted key insights and practical considerations that must precede and underpin each stage of the research process: therefore, we re-emphasize our call to university institutions and funders to develop systems and processes to support researchers and their collaborators throughout these processes, listening carefully to needs, dilemmas, and opportunities, and responding collaboratively. We also echo the call by Vaughn and Jacquez (2020) to document and share the “challenges and facilitators” (p.7) of implementing and developing meaningful participatory research processes, in order that we as a field may learn from across the disciplines, and develop more inclusive, ethical, and respectful research practices.

5. Limitations

Though the review took a broad approach to what counted as “participatory,” using a variety of search terms, other features of the review design likely led to the omission of these bodies of knowledge. Certain participatory approaches were not strongly reflected in this review but were known to the research team. These include citizen science, emancipatory research, inclusive research, and living lab approaches.

The difficulty of representing all forms of participatory research is notable; indeed, future reviews that aim for more comprehensiveness may want to employ their own participatory processes to ensure that conceptually similar research that does not use “participatory” terminology is better represented. Additionally, our inclusion criteria explicitly required studies to report best practices or lessons learned; for the purpose of a rapid scoping review, these were also incorporated as limiting search terms. Thus, if papers did not explicitly state that best practices or lessons learned were being reported, they were not picked up by our search.

Another possible factor is related to the review of reviews design, which necessitated that primary studies had already been captured by an evidence synthesis method and published. Certain fields, especially medical and health sciences, commonly produce systematic and scoping reviews, while other fields may be less likely to publish in this format. While we broadened the search terms to include a variety of evidence syntheses (e.g., “evidence gap map,” “literature review,” “scoping exercise”), we acknowledge there could be a bias away from some disciplines. Still, given the breadth of the disciplines reflected in the review, we feel that the recommendations generally have broader applicability, and we have indicated where best practices are derived from a particular population (e.g., Indigenous communities, cancer patients, etc.) or methodology (e.g., Photovoice).

Our findings on “lessons for academic institutions” are relatively limited, though important. This is possibly a product of primary studies not having space or scope to discuss these issues or best practices. In order for community-engaged methodologies to meaningfully and ethically develop as a research practice, the provision of academic institutional policy surrounding participatory approaches needs to be further explored and promoted.

6. Conclusion

As momentum builds for participatory research across the disciplinary fields, it is important to support more reflective, ethical, and collaborative decisions about the different ways to engage with participatory approaches (Brown, 2021; Vaughn & Jacquez, 2020). It is important to acknowledge the role institutions can play in facilitating and supporting participatory collaborations and to seek better ways to develop meaningful engagement (Wali et al., 2021). This rapid scoping review offers researchers and academic institutions key insights and recommendations for the diverse ways in which they could develop participatory methods within the various stages of their project designs. The review highlights that respect, collaboration, and compromise should underpin all research decisions and that research should be valuable and meaningful to the communities and individuals leading, involved, and impacted by the research.

.....

Declarations

There are no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding Information

This work was funded by the University of Oxford via a grant from the Participatory Research Fund at Research England.

Submitted: November 08, 2022 EDT, Accepted: April 10, 2023 EDT



This is an open-access article distributed under the terms of the Creative Commons Attribution 4.0 International License (CCBY-4.0). View this license's legal deed at <http://creativecommons.org/licenses/by/4.0> and legal code at <http://creativecommons.org/licenses/by/4.0/legalcode> for more information.

References

- Armstrong, A., Aznarez, M., Banks, S., Henfrey, T., Moore, H., Craig, G., Pain, R., & Summerbell, C. (2011). *Community-based Participatory Research: Ethical Challenges*. Durham Community Research Team, Center for Social Justice and Community Action, Durham University. <https://www.durham.ac.uk/media/durham-university/departments-/sociology/Research-Briefing-9---CBPR-Ethical-Challenges.pdf>
- Balazs, C. L., & Morello-Frosch, R. (2013). The three Rs: How community-based participatory research strengthens the rigor, relevance, and reach of science. *Environmental Justice*, 6(1), 9–16. <https://doi.org/10.1089/env.2012.0017>
- Balomenou, N., & Garrod, B. (2016). A Review of Participant-Generated Image Methods in the Social Sciences. *Journal of Mixed Methods Research*, 10(4), 335–351. <https://doi.org/10.1177/1558689815581561>
- Blumenthal, D. S., DiClemente, R. J., Braithwaite, R. L., & Smith, S. A. (Eds.). (2013). *Community-based participatory health research: Issues, methods, and translation to practice*. Springer Publishing Company.
- Boilevin, L., Chapman, J., Deane, L., Doerksen, C., Fresz, G., Joe, D., Leech-Crier, N., Marsh, S., McLeod, J., Neufeld, S. D., Pham, S., Shaver, L., Smith, P., Steward, M., Wilson, D., & Winter, P. (2018). *Research 101: A Manifesto for Ethical Research in the Downtown Eastside*. <http://bit.ly/R101Manifesto>
- Bonello, I., Borg, S., Callus, A.-M., & Grech, C. (2022). Reflections on the Implementation of an Ongoing Inclusive Research Project. *Social Sciences*, 11(6), 234. <https://doi.org/10.3390/socsci11060234>
- Boote, J., Baird, W., & Sutton, A. (2012). Involving the Public in Systematic Reviews: A Narrative Review of Organizational Approaches and Eight Case Examples. *Journal of Comparative Effectiveness Research*, 1(5), 409–420. <https://doi.org/10.2217/cer.12.46>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. <https://doi.org/10.1191/1478088706qp063oa>
- Braun, V., & Clarke, V. (2021). One size fits all? What counts as quality practice in (reflexive) thematic analysis? *Qualitative Research in Psychology*, 18(3), 328–352. <https://doi.org/10.1080/14780887.2020.1769238>
- Brockie, T. N., Hill, K., Davidson, P. M., Decker, E., Koh Krienke, L., Nelson, K. E., Nicholson, N., Werk, A. M., Wilson, D., & Around Him, D. (2021). Strategies for Culturally Safe Research with Native American Communities: An Integrative Review. *Contemporary Nurse*, 58(1), 8–32. <https://doi.org/10.1080/10376178.2021.2015414>
- Brown, N. (2021). Scope and continuum of participatory research. *International Journal of Research & Method in Education*, 45(2), 200–211. <https://doi.org/10.1080/1743727x.2021.1902980>
- Brown, N., & Leigh, J. (2018). Ableism in academia: Where are the disabled and ill academics? *Disability & Society*, 33(6), 985–989. <https://doi.org/10.1080/09687599.2018.1455627>
- Caldera, A. (2020). Strangers Can Make No Noise. In J. A. Van Galen & J. Sablan (Eds.), *Amplified Voices, Intersecting Identities* (Vol. 1, pp. 101–106). Brill. https://doi.org/10.1163/9789004445178_014
- Caldera, A., Rizvi, S., Calderon-Berumen, F., & Lugo, M. (2020). When researching the “Other” intersects with the self: Women of color intimate research. *Departures in Critical Qualitative Research*, 9(1), 63–88. <https://doi.org/10.1525/dcqr.2020.9.1.63>

- Catalani, C., & Minkler, M. (2010). Photovoice: A Review of the Literature in Health and Public Health. *Health Education & Behavior*, 37(3), 424–451. <https://doi.org/10.1177/1090198109342084>
- Centre for Disability Studies. (2021). *Inclusive research*. <https://cds.org.au/promoting-inclusion/inclusive-research/>
- Chandra-Mouli, V., Lenz, C., Adebayo, E., Lundgren, I. L., Garbero, L. G., & Chatterjee, S. (2018). A Systematic Review of the Use of Adolescent Mystery Clients in Assessing the Adolescent Friendliness of Health Services in High, Middle, and Low-Income Countries. *Global Health Action*, 11(1), 1536412. <https://doi.org/10.1080/16549716.2018.1536412>
- Cowdell, F., Dyson, J., Sykes, M., Dam, R., & Pendleton, R. (2022). How and How Well Have Older People Been Engaged in Healthcare Intervention Design, Development or Delivery Using Co-Methodologies: A Scoping Review with Narrative Summary. *Health & Social Care in the Community*, 30(2), 776–798. <https://doi.org/10.1111/hsc.13199>
- Derrick, G. E., Faria, R., Benneworth, B., Budtz-Petersen, G., & Sivertsen, G. (2018, September 12–14). *Towards characterising negative impact: Introducing Grimpect* [Presentation]. 23rd International Conference on Science and Technology Indicators (STI 2018), ‘Science, Technology and Innovation indicators in transition,’ Leiden, The Netherlands. <https://scholarlypublications.universiteitleiden.nl/handle/1887/65230>
- Di Lorito, C., Bosco, A., Birt, L., & Hassiotis, A. (2018). Co-Research with Adults with Intellectual Disability: A Systematic Review. *Journal Of Applied Research In Intellectual Disabilities*, 31(5), 669–686. <https://doi.org/10.1111/jar.12435>
- Duea, S. R., Zimmerman, E. B., Vaughn, L. M., Dias, S., & Harris, J. (2022). A Guide to Selecting Participatory Research Methods Based on Project and Partnership Goals. *Journal of Participatory Research Methods*, 3(1). <https://doi.org/10.35844/001c.32605>
- Espinosa, P. R., & Verney, S. P. (2021). The Underutilization of Community-Based Participatory Research in Psychology: A Systematic Review. *American Journal Of Community Psychology*, 67(3–4), 312–326. <https://doi.org/10.1002/ajcp.12469>
- Fletcher-Watson, S., Adams, J., Brook, K., Charman, T., Crane, L., Cusack, J., Leekam, S., Milton, D., Parr, J. R., & Pellicano, E. (2019). Making the future together: Shaping autism research through meaningful participation. *Autism*, 23(4), 943–953. <https://doi.org/10.1177/1362361318786721>
- Fletcher-Watson, S., Brook, K., Hallett, S., Murray, F., & Crompton, C. J. (2021). Inclusive Practices for Neurodevelopmental Research. *Current Developmental Disorders Reports*, 8(2), 88–97. <https://doi.org/10.1007/s40474-021-00227-z>
- Gast, M. J., Chisholm, J. S., Sivira-Gonzalez, Y., & Douin, T. A. (2022). Racialized moments in qualitative interviews: confronting colour-blind and subtle racism in real time. *International Journal of Research & Method in Education*, 45(3), 284–296. <https://doi.org/10.1080/1743727x.2022.2046726>
- Guillemin, M., & Gillam, L. (2004). Ethics, reflexivity, and “ethically important moments” in research. *Qualitative Inquiry*, 10(2), 261–280. <https://doi.org/10.1177/1077800403262360>
- Guta, A., Wilson, M. G., Flicker, S., Travers, R., Mason, C., Wenyewe, G., & O’Campo, P. (2010). Are We Asking the Right Questions? A Review Of Canadian REB Practices in Relation to Community-Based Participatory Research. *Journal of Empirical Research on Human Research Ethics*, 5(2), 35–46. <https://doi.org/10.1525/jer.2010.5.2.35>
- Habila, M. A., Kimaru, L. J., Mantina, N., Valencia, D. Y., McClelland, D. J., Musa, J., Madhivanan, P., Sagay, A., & Jacobs, E. T. (2021). Community-Engaged Approaches to Cervical Cancer Prevention and Control in Sub-Saharan Africa: A Scoping Review. *Frontiers in Global Women’s Health*, 2(101776281), 697607. <https://doi.org/10.3389/fgwh.2021.697607>

- Hacker, K., Tendulkar, S. A., Rideout, C., Bhuiya, N., Trinh-Shevrin, C., Savage, C. P., Grullon, M., Strelnick, H., Leung, C., & DiGirolamo, A. (2012). Community capacity building and sustainability: outcomes of community-based participatory research. *Progress in Community Health Partnerships: Research, Education, and Action*, 6(3), 349–360. <https://doi.org/10.1353/cpr.2012.0048>
- Harrison, J. D., Auerbach, A. D., Anderson, W., Fagan, M., Carnie, M., Hanson, C., Banta, J., Symczak, G., Robinson, E., Schnipper, J., Wong, C., & Weiss, R. (2019). Patient Stakeholder Engagement in Research: A Narrative Review to Describe Foundational Principles and Best Practice Activities. *Health Expectations*, 22(3), 307–316. <https://doi.org/10.1111/hex.12873>
- Hubbard, G., Kidd, L., Donaghy, E., McDonald, C., & Kearney, N. (2007). A Review of Literature about Involving People Affected by Cancer in Research, Policy and Planning and Practice. *Patient Education and Counseling*, 65(1), 21–33. <https://doi.org/10.1016/j.pec.2006.02.009>
- Jason, L., & Glenwick, D. (Eds.). (2016). *Handbook of methodological approaches to community-based research: Qualitative, quantitative, and mixed methods*. Oxford University Press.
- Jennings, H., Slade, M., Bates, P., Munday, E., & Toney, R. (2018). Best Practice Framework for Patient and Public Involvement (PPI) in Collaborative Data Analysis of Qualitative Mental Health Research: Methodology Development and Refinement. *BMC Psychiatry*, 18(1). <https://doi.org/10.1186/s12888-018-1794-8>
- Jivraj, J., Sacrey, L.-A., Newton, A., Nicholas, D., & Zwaigenbaum, L. (2014). Assessing the influence of researcher–partner involvement on the process and outcomes of participatory research in autism spectrum disorder and neurodevelopmental disorders: A scoping review. *Autism*, 18(7), 782–793. <https://doi.org/10.1177/1362361314539858>
- Jumarali, S. N., Nnawulezi, N., Royson, S., Lippy, C., Rivera, A. N., & Toopet, T. (2021). Participatory Research Engagement of Vulnerable Populations: Employing Survivor-Centered, Trauma-Informed Approaches. *Journal of Participatory Research Methods*, 2(2). <https://doi.org/10.35844/001c.24414>
- Le Cunff, A. L., Ellis Logan, P., Ford, R., Martis, B. L., Mousset, I., Sekibo, J., Dommett, E., & Giampietro, V. (2023). Co-Design for Participatory Neurodiversity Research: Collaborating With a Community Advisory Board to Design a Research Study. *Journal of Participatory Research Methods*, 4(1). <https://doi.org/10.35844/001c.661841>
- Leavy, P. (2017). *Research design: Quantitative, qualitative, mixed methods, arts-based, and community-based participatory research approaches*. Guilford Publications. <https://doi.org/10.1111/fcsr.12276>
- Lenette, C. (2022). Cultural Safety in Participatory Arts-Based Research: How Can We Do Better? *Journal of Participatory Research Methods*, 3(1). <https://doi.org/10.35844/001c.32606>
- Lenette, C., Stavropoulou, N., Nunn, C., Kong, S. T., Cook, T., Coddington, K., & Banks, S. (2019). Brushed under the carpet: Examining the complexities of participatory research. *Research for All*, 3(2), 161–179. <https://doi.org/10.18546/RFA.03.2.0>
- Levac, L., Ronis, S., Cowper-Smith, Y., & Vaccarino, O. (2019). A Scoping Review: The Utility of Participatory Research Approaches in Psychology. *Journal of Community Psychology*, 47(8), 1865–1892. <https://doi.org/10.1002/jcop.22231>
- Marrone, N. L., Nieman, C. L., & Coco, L. (2022). Community-based participatory research and human-centered design principles to advance hearing health equity. *Ear & Hearing*, 43(Supplement 1), 33S–44S. <https://doi.org/10.1097/aud.0000000000001183>
- Marzi, S. (2021). Participatory video from a distance: co-producing knowledge during the COVID-19 pandemic using smartphones. *Qualitative Research*, 0(0), 1468794121110381. <https://doi.org/10.1177/146879412111038171>

- Marzi, S., & Pain, R. (2022, June 20). The next REF should place greater value on the ‘impact-in-process’ generated by co-produced research. *Impact of Social Sciences Blog*. <https://blogs.lse.ac.uk/impactofsocialsciences/2022/06/20/the-next-ref-should-place-greater-value-on-the-impact-in-process-generated-by-co-produced-research/>
- McElfish, P. A., Yearly, K., Sinclair, K. A., Steelman, S., Esquivel, M. K., Aitaoto, N., Kaholokula, K., Purvis, R. S., & Ayers, B. L. (2019). Best Practices for Community-Engaged Research with Pacific Islander Communities in the US and USAPI: A Scoping Review. *Journal of Health Care for the Poor and Underserved*, 30(4), 1302–1330. <https://doi.org/10.1353/hpu.2019.0101>
- Minkler, M., Garcia, A. P., Rubin, V., & Wallerstein, N. (2012). *Community-based participatory research: A strategy for building healthy communities and promoting health through policy change*. PolicyLink. <https://www.policylink.org/resources-tools/building-healthy-communities-and-promoting-health-through-policy-change>
- Moore, G., Wilding, H., Gray, K., & Castle, D. (2019). Participatory Methods to Engage Health Service Users in the Development of Electronic Health Resources: Systematic Review. *Journal of Participatory Medicine*, 11(1), e11474. <https://doi.org/10.2196/11474>
- Moses, M. (2022). Methodologically disrupting whiteness: a critical race case for visual-elicited focus groups as cultural responsiveness. *International Journal of Research & Method in Education*, 45(3), 297–308. <https://doi.org/10.1080/1743727x.2022.2043844>
- Muller-Schoof, I. J. M., Verbiest, M. E. A., Snoeren, M., & Luijckx, K. G. (2023). Lessons Learned From Co-Designing Educational Programs for Student and Practicing Healthcare Professionals in Nursing Homes: A Participatory Qualitative Study. *Journal of Participatory Research Methods*, 4(1). <https://doi.org/10.35844/001c.57529>
- Nind, M., Kara, H., Erel, U., Barnes, H. M., Chilisa, B., & Boulton, A. (2017). Reflective commentaries. *Qualitative Research*, 17(3), 351–355. <https://doi.org/10.1177/1468794117698915>
- Nunn, J. S., Tiller, J., Fransquet, P., & Lacaze, P. (2019). Public Involvement in Global Genomics Research: A Scoping Review. *Frontiers in Public Health*, 7. <https://doi.org/10.3389/fpubh.2019.00079>
- Oberschmidt, K., Grünloh, C., Nijboer, F., & van Velsen, L. (2022). Best Practices and Lessons Learned for Action Research in eHealth Design and Implementation: Literature Review. *Journal of Medical Internet Research*, 24(1), e31795. <https://doi.org/10.2196/31795>
- O’Brien, J., Fossey, E., & Palmer, V. J. (2021). A Scoping Review of the Use of Co-Design Methods with Culturally and Linguistically Diverse Communities to Improve or Adapt Mental Health Services. *Health & Social Care in the Community*, 29(1), 1–17. <https://doi.org/10.1111/hsc.13105>
- Oyana, T. J. (2017). The use of GIS/GPS and spatial analyses in community-based participatory research. *Handbook of Community-Based Participatory Research*, 39–56. <https://doi.org/10.1093/acprof:oso/9780190652234.003.0004>
- Phillips, L., Larsen, A., & Mengel, L. (2022). What “Coproduction” in Participatory Research Means From Participants’ Perspectives: A Collaborative Autoethnographic Inquiry. *Journal of Participatory Research Methods*, 3(2). <https://doi.org/10.35844/001c.37638>
- Resnik, D. B., & Kennedy, C. E. (2010). Balancing scientific and community interests in community-based participatory research. *Accountability in Research*, 17(4), 198–210. <https://doi.org/10.1080/08989621.2010.493095>
- Rix, J., Carrizosa, H. G., Sheehy, K., Seale, J., & Hayhoe, S. (2022). Taking risks to enable participatory data analysis and dissemination: a research note. *Qualitative Research*, 22(1), 143–153. <https://doi.org/10.1177/1468794120965356>

- Rizvi, S. (2022a). Racially-just epistemologies and methodologies that disrupt whiteness. *International Journal of Research & Method in Education*, 45(3), 225–231. <https://doi.org/10.1080/1743727x.2022.2073141>
- Rizvi, S. (2022b). Racially-just epistemologies and methodologies that disrupt whiteness (part II). *International Journal of Research & Method in Education*, 45(4), 323–329. <https://doi.org/10.1080/1743727x.2022.2117519>
- Satcher, D. (2005). *Methods in community-based participatory research for health*. John Wiley & Sons.
- Scheim, A. I., Souleymanov, R., Kuzmanovic, D., Marshall, Z., Worthington, C., Mikiki, M., & Milson, P. (2015). Ethics in Community-Based Research with People Who Use Drugs: A Scoping Review and Community Resource. *Canadian Journal of Infectious Diseases and Medical Microbiology*, 26(SUPPL. SB), 110B. <https://doi.org/10.1186/s12910-016-0108-2>
- Shen, S. Q., Doyle-Thomas, K. A. R., Beesley, L., Karmali, A., Williams, L., Tanel, N., & McPherson, A. C. (2017). How and why should we engage parents as co-researchers in health research? A scoping review of current practices. *Health Expectations*, 20(4), 543–554. <https://doi.org/10.1111/hex.12490>
- Shippee, N. D., Domecq Garces, J. P., Prutsky Lopez, G. J., Wang, Z., Elraiyah, T. A., Nabhan, M., Brito, J. P., Boehmer, K., Hasan, R., Firwana, B., Erwin, P. J., Montori, V. M., & Murad, M. H. (2015). Patient and Service User Engagement in Research: A Systematic Review and Synthesized Framework. *Health Expectations*, 18(5), 1151–1166. <https://doi.org/10.1111/hex.12090>
- Smith, H., Budworth, L., Grindey, C., Hague, I., Hamer, N., Kislov, R., van der Graaf, P., & Langley, J. (2022). Co-Production Practice and Future Research Priorities in United Kingdom-Funded Applied Health Research: A Scoping Review. *Health Research Policy and Systems*, 20(1). <https://doi.org/10.1186/s12961-022-00838-x>
- Spiel, K., Brulé, E., Frauenberger, C., Bailey, G., & Fitzpatrick, G. (2020). In the details: the micro-ethics of negotiations and in-situ judgements in participatory design with marginalised children. *CoDesign*, 16(1), 45–65. <https://doi.org/10.1080/15710882.2020.1722174>
- Thomas, S. N., Weber, S., & Bradbury-Jones, C. (2022). Using Participatory and Creative Methods to Research Gender-Based Violence in the Global South and With Indigenous Communities: Findings From a Scoping Review. *Trauma, Violence, & Abuse*, 23(2), 342–355. <https://doi.org/10.1177/1524838020925775>
- Tricco, A. C., Antony, J., Zarin, W., Striffler, L., Ghassemi, M., Ivory, J., Perrier, L., Hutton, B., Moher, D., & Straus, S. E. (2015). A scoping review of rapid review methods. *BMC Medicine*, 13(1), 1–15. <https://doi.org/10.1186/s12916-015-0465-6>
- Vaccaro, M. E. (2020). Reflections on ‘doing’ participatory data analysis with women experiencing long-term homelessness. *Action Research*, 1476750320974429. <https://doi.org/10.1177/147675032097442>
- Vaughn, L. M., & Jacquez, F. (2020). Participatory Research Methods – Choice Points in the Research Process. *Journal of Participatory Research Methods*, 1(1). <https://doi.org/10.35844/001c.13244>
- Viswanathan, M., Ammerman, A., Eng, E., Garlehner, G., Lohr, K. N., Griffith, D., Rhodes, S., Samuel-Hodge, C., Maty, S., Lux, L., Webb, L., Sutton, S. F., Swinson, T., Jackman, A., & Whitener, L. (2004). *Community-based participatory research: Assessing the evidence*. AHRQ Evidence Report Summaries.
- Wali, S., Superina, S., Mashford-Pringle, A., Ross, H., & Cafazzo, J. A. (2021). 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. *International Journal for Equity in Health*, 20(1). <https://doi.org/10.1186/s12939-020-01346-6>

- Wallerstein, N. (2020). Commentary on Community-Based Participatory Research and Community Engaged Research in Health for Journal of Participatory Research Methods. *Journal of Participatory Research Methods*, 1(1). <https://doi.org/10.35844/001c.13274>
- Wallerstein, N., & Duran, B. (2010). Community-based participatory research contributions to intervention research: the intersection of science and practice to improve health equity. *American Journal of Public Health*, 100(S1), S40–S46. <https://doi.org/10.2105/AJPH.2009.184036>
- Wallerstein, N., Oetzel, J. G., Sanchez-Youngman, S., Boursaw, B., Dickson, E., Kastelic, S., Koegel, P., Lucero, J. E., Magarati, M., Ortiz, K., Parker, M., Peña, J., Richmond, A., & Duran, B. (2020). Engage for equity: A long-term study of community-based participatory research and community-engaged research practices and outcomes. *Health Education & Behavior*, 47(3), 380–390. <https://doi.org/10.1177/1090198119897075>
- Wilson, E., Kenny, A., & Dickson-Swift, V. (2018). Ethical Challenges in Community-Based Participatory Research: A Scoping Review. *Qualitative Health Research*, 28(2), 189–199. <https://doi.org/10.1177/10497323176907>
- Wine, O., Ambrose, S., Campbell, S., Villeneuve, P. J., Kovacs Burns, K., Osornio Vargas, A., & The DoMiNO Team. (2017). Key components of collaborative research in the context of environmental health: A scoping review. *Journal of Research Practice*, 13(2). <http://jrp.icaap.org/index.php/jrp/article/view/577/477>
- Zimmerman, E. B., Haley, A., Creighton, G. C., Bea, C., Miles, C., Robles, A., Cook, S., & Aroche, A. (2019). Assessing the impacts and ripple effects of a community-university partnership: A retrospective roadmap. *Michigan Journal of Community Service Learning*, 25(1), 62–76. <https://doi.org/10.3998/mjcsloa.3239521.0025.106>

Appendix

Supplemental Table 1. Summary of search strings and used in databases

Database	Search String	Number of Hits
Web of Science	((TS=("participatory research" OR "co-production" OR "action research" OR "engage* research" OR "community-based research" OR "community-based participatory research")) AND TS=("participatory research design" OR "participatory research method*" OR "research exemplars" OR "best practic*" OR "good practice")) AND TS=("systematic review" OR "scoping review" OR "scoping study" OR "scoping exercise" OR "systematic map* review" OR "rapid review" OR "evidence map*" OR "systematic scoping review")	37
SCOPUS	(TITLE-ABS-KEY ("participatory research" OR "co-production" OR "action research" OR "engage* research" OR "community-based research" OR "community-based participatory research") AND TITLE-ABS-KEY ("participatory research design" OR "participatory research method*" OR "research exemplars" OR "best practic*" OR "good practice") AND TITLE-ABS-KEY ("systematic review" OR "scoping review" OR "scoping study" OR "scoping exercise" OR "systematic map* review" OR "rapid review" OR "evidence map*" OR "systematic scoping review"))	47
ProQuest	noft("participatory research" OR "co-production" OR "action research" OR "engage* research" OR "community-based research" OR "community-based participatory research") AND noft("participatory research design" OR "participatory research method*" OR "research exemplars" OR "best practic*" OR "good practice") AND noft("systematic review" OR "scoping review" OR "scoping study" OR "scoping exercise" OR "systematic map* review" OR "rapid review" OR "evidence map*" OR "systematic scoping review")	33
Pub Med	((("participatory research"[Title/Abstract] OR "co-production"[Title/Abstract] OR "action research"[Title/Abstract] OR "engage* research"[Title/Abstract] OR "community-based research"[Title/Abstract] OR "community-based participatory research"[Title/Abstract]) AND ("participatory research design"[Title/Abstract] OR "participatory research method*" [Title/Abstract] OR "research exemplars"[Title/Abstract] OR "best practic*" [Title/Abstract] OR "good practice"[Title/Abstract])) AND ("systematic review"[Title/Abstract] OR "scoping review"[Title/Abstract] OR "scoping study"[Title/Abstract] OR "scoping exercise"[Title/Abstract] OR "systematic map* review"[Title/Abstract] OR "rapid review"[Title/Abstract] OR "evidence map*" [Title/Abstract] OR "systematic scoping review"[Title/Abstract])	24
OVID (including Medline, PschyInfo/ EMBASE, APAPsych)	KEYWORD(participatory research) OR (co-production) OR (action research) OR (engage* research) OR (community-based research) OR (community-based participatory research)KEYWORD(participatory research design) OR (participatory research method*) OR (research exemplars) OR (best practic*) OR (good practice)KEYWORD(systematic review) OR (scoping review) OR (scoping study) OR (scoping exercise) OR (systematic map* review) OR (rapid review) OR (evidence map*) OR (systematic scoping review)	134

Supplemental Table 2. Themes and Subthemes

Theme	Subtheme	Recommendations
Participatory Research Recommendations for Researchers	3.2 Early-Stage Considerations for Study Design and Planning	3.2.1. Build Relationships and Trust with Individuals and Community Stakeholder Groups
		3.2.2. Engage Community Members Throughout the Research Process
		3.2.3. Employ a Collaborative Approach in the Design of Ethical Protocols
		3.2.4. Seek to Understand Cultural Context and Respect Cultural Norms
		3.2.5. Build Capacity for Participation in the Community of Interest
	3.3. Conducting the Research	3.3.1. Provide Varied and Flexible Avenues for Participation
		3.3.2. Involve Community Members in Data Collection
		3.3.3. Consider If and How to Compensate Participants
		3.3.4. Anticipate Flexible Timelines
		3.3.5. Consider Special Budgetary Needs
3.3.6. Leverage staff and Structural Supports		
3.3.7. Maintain Clear Communication, Expectations and Feedback		
3.3.8. Ensure Shared Decision-Making and Reflexivity		
3.4. Dissemination and Knowledge Exchange	3.4.1. Ensure Appropriate Reporting of Research Designs and Procedures in Publications	
	3.4.2. Include Community Members in Dissemination	
Participatory Research Recommendations for Academic Institutions		

Supplemental Table 3. Examples of Protocols and Frameworks for Participatory Research

Citation	Population/ Setting	Topic
Wright et al. (2021). Our journey, our story: a study protocol for the evaluation of a co-design framework to improve services for Aboriginal youth mental health and well-being <i>BMJ Open</i> 11:e042981. http://dx.doi.org/10.1136/bmjopen-2020-042981	Aboriginal youth in Western Australia	Mental health and well-being
Neufeld et al. (2019). Research 101: A process for developing local guidelines for ethical research in heavily researched communities. <i>Harm Reduct J</i> 16(41). https://doi.org/10.1186/s12954-019-0315-5	Marginalized communities in Vancouver, Canada	Community ethics
Zuber-Skerritt, O. (2018). An educational framework for participatory action learning and action research (PALAR). <i>Educational Action Research</i> , 26(4), 513-532, https://doi.org/10.1080/09650792.2018.1464939	Education	Learning, teaching, assessment, and leadership development
Bagley et al. (2016). A patient and public involvement (PPI) toolkit for meaningful and flexible involvement in clinical trials - a work in progress. <i>Res Involv Engagem.</i> 27(2), 15. https://doi.org/10.1186/s40900-016-0029-8	Healthcare patients	Increasing patient and public involvement in clinical trials
Mental Health Experience Co-Design (MH ECO). https://tandemcarers.org.au/Web/Web/Resources/Research-Projects/MH-ECO.aspx	Recipients of mental health services	Improving quality and experience of mental health care services
Experience-Based Co-Design (EBCD). https://www.pointofcarefoundation.org.uk/resource/experience-based-co-design-ebcd-toolkit/	Healthcare patients	Improving experience of healthcare services
Metro-Regional Intellectual Disability Network (MRID) Co-Design Kit. http://codesignkit.org.au/co-design-in-practice/co-design-from-scratch/	Individuals with intellectual disabilities	Improving healthcare services