Participatory approaches in the development of health interventions for migrants: a systematic review

Kieran Rustage 1, Alison Crawshaw,1 Salilha Majeed-Hajaj,2 Anna Deal,1,3 Laura Nellums 4, Yusuf Ciftci,5 Sebastian S Fuller,1 Lucy Goldsmith,1,6 Jon S Friedland,1 Sally Hargreaves1

ABSTRACT

Objective Analysis of participatory approaches to developing health interventions for migrants and how approaches embody core participatory principles of inclusivity and democracy.

Design A systematic review of original articles. Electronic searches within the databases MEDLINE, Embase, Global Health and PsycINFO (from inception—November 2020).

Eligibility criteria for study selection Original peer-reviewed articles reporting research to develop and implement a health intervention for migrants, incorporating participatory approaches. We defined migrants as foreign-born individuals. Only articles reporting the full research cycle (inception, design, implementation, analysis, evaluation, dissemination) were included.

Data extraction We extracted information related to who was involved in research (migrants or other non-academic stakeholders), the research stage at which they were involved (inception, design, implementation, analysis, evaluation, dissemination), the method of their involvement and how this aligned with the core principles of participatory research—categorising studies as exhibiting active or pseudo (including proxy and indirect) participation.

Results 1793 publications were screened, of which 28 were included in our analysis. We found substantial variation in the application of participatory approaches in designing health interventions targeting migrants: across 168 individual research stages analysed across the 28 studies, we recorded 46 instances of active participation of migrants, 30 instances of proxy participation and 24 instances of indirect participation. All studies involved non-academic stakeholders in at least one stage of the research, only two studies exhibited evidence of active participation of migrants across all research stages. Evidence is limited due to the variability of terms and approaches used.

Conclusions Important shortfalls in the meaningful inclusion of migrants in developing health interventions exist, suggesting a more rigorous and standardised approach is warranted to better define and deliver participatory research and improve quality.

Registration This review followed Preferred Reporting Items for Systematic Review and Meta-Analysis guidelines and is registered on the Open Science Framework (osf.io/2bnz5).

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ This systematic review represents a robust and novel assessment of the application of participatory approaches and principles towards research into health interventions involving migrants.

⇒ This review casts a critical lens over the relationship between how participatory approaches are applied and how participatory principles such as inclusivity and democracy are embodied.

⇒ Due to the varied and interchangeable use of participatory research terms, the categorisations and definitions we use could be interpreted differently by others.

⇒ This review is limited by the lack of clear and consistent reporting participatory methods used, suggesting that guidelines must be developed and more consistently adopted to improve transparency in all participatory research.

⇒ This review does not address possible associations between participatory methods and final health or research outcomes, which should be better considered in future research.

INTRODUCTION

Considerable emphasis is now being placed on ensuring patient and public engagement in health research, including striving for greater involvement of marginalised groups such as migrants and ethnic minorities.1,2 However, whether this is effectively and meaningfully done in practice to ensure truly patient-centred research has yet to be fully elucidated. Participatory research represents a distinct research paradigm in which research is done collaboratively with the individuals whose lived experiences and actions are the subject of study, as active partners who share power and influence over research processes and outcomes.3-6

Two fundamental principles of participatory research that underpin the ability for stakeholders to effectively co-operate and share power are those of inclusivity
and democracy, particularly in relation to those directly affected by the research in question. That is to say, has the research included the individuals the research would otherwise be about, and have these individuals, during their inclusion, had influence or power over research decisions on par with the research professionals? Included under the umbrella of participatory research approaches are more specific methodologies, which look to uphold these principles, including: community-based participatory research (CBPR); action research; some patient & public involvement as well as broader derivatives such as community-based collaborative action research. Participatory research holds the potential to bridge the gap between public health research and practice, creating a context in which patients and the public have meaningful influence over research decisions, increasing the relevance and impact of research outcomes to their own lives.

Participatory research is likely to be particularly powerful when working with underserved and marginalised groups such as migrants, where traditional research has frequently failed to provide an appreciable health benefit. While a heterogeneous group, comprising a multitude of cultures, ethnicities and sociocultural circumstances, many migrants can find themselves in vulnerable situations, marginalised by health systems and society alike. There is a growing consensus around the need for academics and health systems to become more responsive to, and inclusive of refugee and migrant health concerns. Indeed, limited community engagement in public health interventions has already been shown to be effective when working with marginalised groups around a range of health outcomes and can provide benefits to participants themselves, such as in improving health behaviours and participant self-efficacy. However, the ultimate goal is to conduct participatory research with migrants as a matter of routine, so that research is better centred around and grounded in the needs of migrant communities.

Despite the potential of participatory research, there are varied interpretations as to how to apply such approaches. A review of peer models in participatory research, in which partnerships with ‘insiders’ are established reveal a norm in which practices and terms are interchangeable and inconsistently applied. Challenges exist in deciding who should be involved, and whether involvement should extend beyond the target group (in this case, migrants), to other non-academic stakeholder groups such as community organisations and professionals. There are also differing interpretations of the degree of participation required of individuals for research to be considered participatory rather than tokenistic, though it is suggested that unless involved individuals are partners or coresearchers throughout the entirety of a project, the work cannot be participatory. Overall, it is widely agreed that quality participation is characterised by non-academic stakeholders having opportunities to engage with, make decisions about and perform leadership roles around such research, empowering the public at the highest level and asserting their right to be involved in decision-making and to influence outcomes. Understanding the different approaches to participatory research and whether the core principles of participatory research are upheld is crucially important if good practice is to be identified.

We, therefore, did a systematic review to analyse participatory approaches in the development of health interventions for migrants, through use of a framework, which relates categories of participation to core principles of participation (inclusivity and democracy), and collates evidence of the benefits of using a participatory approach to research, and of the challenges of using a participatory approach to research.

METHODS
We did a systematic review, following Preferred Reporting Items for Systematic Review and Meta-Analysis guidelines, which is registered on the Open Science Framework. The primary aim of this systematic review was to analyse the use of participatory approaches to develop health interventions targeting migrants as the intended beneficiaries. Specifically, we established a framework of categories of participation, which related the data we extracted to participatory principles of inclusivity and democracy. Our secondary aims were to describe the challenges and benefits of using participatory approaches experienced in the research process.

Inclusion and exclusion criteria
We included peer-reviewed primary-research reporting on health research into interventions aimed at benefitting migrant populations that described using a participatory approach across the whole research process. Research that purported to use a participatory research approach through descriptors in their introduction and methods, or which used a recognised participatory approach such as CBPR, action research or community-based collaborative action research and specifically targeted migrants was included in the review. We defined migrants as foreign-born individuals and considered a health intervention to be any initiative, tool or programme that looked to improve health outcomes, including those related to mental health and health literacy.

Studies were excluded if they did not report on all stages of research into the health intervention: inception, design, implementation, analysis, evaluation, dissemination.

As such, publications presenting interim results of studies which had not completed the full research cycle as well as studies specifically focusing on only codesigning interventions were excluded. We took this approach so as not to unfairly penalise ongoing research in our analysis, nor codesigned research; we consider codesign to be one component of the broader participatory research paradigm and were most interested in how approaches
manifest across the entirety of a research cycle. Studies explicitly defining migrant status according to ethnic or ancestral background but not country of birth were excluded, as were papers where primary data were not reported (eg, comments, editorials, letters and reviews).

**Search strategy**

We individually searched the databases MEDLINE (1946—November 2020), Embase (1974—November 2020), Global Health (1910—November 2020) and PsychINFO (1967—November 2020) within the Ovid platform using a Boolean search strategy with keywords and medical subheadings related to two major themes: migrants and participatory research. There were no geographic or language restrictions. An additional text file outlines the full searches carried out (see online supplemental file 1). The retrieved hits from each database were combined and deduplicated manually within Rayyan. We identified additional studies through hand searching the bibliographies of publications included after full-text screening.

**Study selection**

Two reviewers duplicated the title and abstract screening and full-text screening (KR and SM-H), which was carried out using the web-based application Rayyan.19 The reasons for excluding studies during full-text screening were recorded. Any discrepancies in screening decision between the two initial reviewers were mediated by a third reviewer (AC), where retrieved articles indicated the existence of a separate methodological article, we also screened this in conjunction with the first article on condition that it was a retrospective report of methods used (across all stages of the research) rather than a prospective outline of planned methods.

**Data extraction and analysis**

Studies that reported using participatory research approaches, and which reported on all stages of the research, were extracted using a piloted form by KR and SH. We extracted summary data on geographical location, the self-described participatory approach, specific target population and aims of the research. Data relating to the participatory approach of each study were extracted and analysed to achieve our primary aim. We extracted data on the stages of the research in which migrants were involved (table 1), where specific research stages did not involve migrants but did involve other non-academic stakeholders this was recorded, subcategorising these groups as community groups/third-sector organisations or professional services. We subsequently extracted data on the methods used to involve migrants (or other non-academic stakeholders) at each stage of the research (inception, design, implementation, analysis, evaluation and dissemination). An additional file provides details of the summary extracted data (see online supplemental file 2).

We related extracted information on who was involved, when they were involved and how they were involved in the described research, relating these factors to participatory principles of inclusion and democracy and categorising them within a framework we developed (table 2). The framework was developed with reference to the literature, particularly that relating to participatory research as a democratic process and being necessary to implement at all stages of the research.3 5 18 20 We used data extracted as to who was involved, and when, to guide our assessment of inclusivity. Specifically, we were concerned with whether the evidence displayed relevant inclusivity, that is, the involvement of migrant individuals that are the target or intended beneficiary of the health intervention. We used data extracted as to the method and means of involvement to guide our assessment of democracy. In this instance, we sought evidence of whether methods employed in the research suggested greater levels of democracy, such as through power-sharing and decision-making mechanisms such as equal voting, or committees for those involved. Within the framework, we categorised the aggregated data from each study, with specific reference to migrant individuals, as: active participation; pseudo participation (including proxy and indirect participation) or no explicit evidence of participation. The final framework and definitions were agreed by all coauthors (table 2).

To achieve our secondary aim, we specifically scanned the included articles for evidence of any evaluation of

| Table 1 | Stages of research and evidence sought for each stage during data extraction |
|---------|--------------------------------------------------------------------------------|
| **Research stages** | **Inception** | **Design** | **Implementation** | **Analysis** | **Evaluation** | **Dissemination** |
| **Evidence sought** | Who was responsible for having the idea for the research or initiating the study? | Who was involved in the initial planning and design of the intervention/ study? | Who decided what the final design of the intervention/ study would be? | Who was responsible for implementing/ piloting the intervention within the remit of the study? | Who decided what these implementation should look like? | Who was involved in analysing data relating to primary endpoints/ outcomes? | Who decided what these endpoints or outcomes should be? | Who was involved in the overall evaluation of the intervention/ study? For example, process evaluation, reflective evaluation? | Who had a say in determining successes/ failures/future considerations? | Who was involved in disseminating findings? What form did this take? | Who decided this? |

Rustage K, et al. BMJ Open 2021;11:e053678. doi:10.1136/bmjopen-2021-053678
| Category of participation | Definition | Criteria | Relationship to participatory principles |
|---------------------------|------------|----------|------------------------------------------|
| Active participation      | Migrants appeared to be both actively involved, and wielded influence in decisions relating to the research. | ▶ Migrant individuals were involved in this stage of the research. And ▶ Individuals involved appeared to have direct power and influence over the research stage through shared processes with researchers such as voting or committees. | Relevant inclusivity and greater democracy with regards to migrant involvement. |
| Pseudo participation      | Community/third-sector organisations and/or professional services are actively involved and wield influence in decisions related to the research stage ahead (or in lieu) of migrants. | ▶ There is uncertain/no clear evidence migrant individuals were involved. Or ▶ Where migrant individuals were involved, they did not appear to have direct power and influence over the research through shared processes with researchers such as voting or committees. Rather, they were appeared to be involved as research subjects, in surveys or focus groups. But ▶ Third-sector organisations and/or professional services were involved. And ▶ Third-sector organisation and/or professional services appeared to have direct power and influence over the research stage through shared processes with researchers such as voting or committees. | There may be relevant inclusivity, but lesser democracy with regards to migrant involvement. There may be greater democracy with other stakeholders. |
| Indirect participation    | Migrants’ involvement is restricted to activities in which they are research subjects (surveys, focus groups, interviews). No other stakeholders appear to be involved. | ▶ Where migrant individuals were involved, they did not appear to have direct power and influence over the research through shared processes with researchers such as voting or committees. Rather, they appeared to be involved as research subjects, in surveys or focus groups. And ▶ There is uncertain/no clear evidence as to the involvement of third-sector organisations or professional services. | There may be relevant inclusivity, but lesser democracy with regards to migrant involvement. There is no clear evidence of inclusivity or democracy with other stakeholders. |

Continued
the use of participatory approaches within the research, inclusive of reflections that appeared in the discussion of included articles. We extracted this data, where found, and categorised it as representing a challenge or benefit associated with the use of participatory approaches toward the overall research process.

**Patient and public involvement**

Members of our authorship team have past and current experience of working within third-sector organisations. This experience helped to frame the research questions and definitions used in the analysis. However, lay patients and public specifically were not involved in this research.

**RESULTS**

**Screening results**

Database searches returned 1793 results; a total of 292 duplicates were removed and 1501 publications were retained for title and abstract screening. Of the 1501 remaining publications, 1357 were excluded during title and abstract screening and 144 were retained for full-text screening. During full-text screening, 116 publications did not meet our criteria and were excluded, with the reasons for exclusion recorded (figure 1). Overall, 28 publications met the inclusion criteria and were included in this systematic review (table 3).

**Study characteristics**

The research articles included in this systematic review were published between 2003 and 2019. Only 13 of the publications had any discernible dates relating to when the reported work was conducted, with these dates being between 2003 and 2018. The majority of the publications related to work were carried out in the USA (24 out of 28); the remaining publications related to work were carried out in Canada, Lebanon, Thailand and the UK. The self-described approach taken by 24 of the 28 included studies was CBPR, the remaining four studies were described using community-based collaborative-action research, community-based outreach and action research. The dominant focus of the included studies was around education or outreach (table 3), for example, around cancer education, or healthy lifestyles promotion; five studies specifically mentioned, including refugees (table 3).

**Analysis of participatory approaches in research to develop health interventions for migrants**

In our analysis, participation varied substantially according to the stage of the research under scrutiny. Only two of the included studies reported explicit evidence of some degree of participation of at least one non-academic stakeholder group across all research stages (table 4). Overall, we extracted and categorised evidence of the participation of at least one non-academic stakeholder group in 22 studies during the inception, 21–25 26 29–34 36 38–40 42–48 25 studies during the

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**Table 2** Continued

| Category of participation | Definition | Criteria | Relationship to participatory principles |
|---------------------------|------------|----------|----------------------------------------|
| No explicit evidence      | No non-academic stakeholders (migrant or otherwise) appear to be involved in this stage of the research. | - There is no clear evidence as to the involvement of migrant individuals.  
- There is no clear evidence as to the involvement of third-sector organisations or professional services. | There is no clear evidence of inclusivity or democracy with migrants or other stakeholders. |

Figure 1  Preferred Reporting Items for Systematic Review and Meta-Analysis flow diagram of the study selection process.
### Table 3 Descriptive characteristic of studies included in this systematic review

| Citation         | Location | Self-described participatory approach/methodology | Specific target population             | Aim of the health intervention                                                                 |
|------------------|----------|--------------------------------------------------|----------------------------------------|------------------------------------------------------------------------------------------------|
| Afifi et al.⁴²    | Lebanon  | Community-based participatory research (CBPR)     | Palestinian refugee youth              | Mental health promotion                                                                         |
| Aitaoto et al.⁴⁵ | USA      | CBPR                                             | Micronesian women                      | Cancer outreach/education                                                                       |
| Baird et al.¹⁷   | USA      | Community-based collaborative-action research    | Sudanese refugee women                 | Addressing health challenges associated with relocation                                        |
| Barbee et al.⁶⁶  | USA      | CBPR                                             | Haitian immigrant women                | To assess the acceptability of human papillomavirus (HPV) self-sampling with community health workers to detect cervical cancer |
| Chesla et al.²⁷  | USA      | CBPR                                             | Chinese-American Immigrants            | To culturally adapt coping skills training for type-2 diabetes (T2DM)                           |
| Evans et al.²⁴   | UK       | CBPR                                             | African migrants                       | To promote HIV testing uptake                                                                    |
| Forst et al.²⁸   | USA      | CBPR                                             | Hispanic construction workers          | To increase awareness of workplace hazards and self-efficacy; expansion of worker centre agenda to include occupation health and safety |
| Goodkind et al.²⁹| USA      | CBPR                                             | Afghan, Great lakes Region African and Iraqi refugee adults | To address social determinants of health; to improve linkage to mental health services and retention in trauma-focused treatment |
| Grigg-Saito et al.⁴⁸ | USA      | Community-Based Outreach                         | Cambodian immigrants                   | Strength-based outreach to eliminate cardiovascular disease and diabetes disparities            |
| Henderson and Slater²¹ | Canada | Action Research                                 | Newly arrived migrants                 | To provide tailored nutritional information and support                                          |
| Jacquez et al.³⁰ | USA      | CBPR                                             | Latino immigrants                      | Stress reduction                                                                                 |
| Kaiser et al.³¹  | USA      | CBPR                                             | Mexican immigrants                     | To provide obesity prevention education & outreach                                               |
| Kandula et al.³² | USA      | CBPR                                             | South Asian immigrant women            | Exercise intervention for those at risk of diabetes                                             |
| Karasz et al.³³  | USA      | CBPR                                             | Bangladeshi immigrant women            | To provide and intervention tackling common mental disorders                                   |
| Kim et al.³⁴     | USA      | CBPR                                             | Latino immigrants                      | To use lay health advisors for cardiovascular health promotion                                  |
| Lam et al.³⁵     | USA      | CBPR                                             | Vietnamese immigrants                  | To increase pap screening through education and outreach through lay health workers and media   |
| Li et al.³⁶      | USA      | CBPR                                             | Chinese-American immigrants            | To prevent colorectal cancer through education and outreach                                      |
| Nilvarangkul et al.³³ | Thailand | Action Research                                 | Laotian migrants                       | Enhancement of a quality-of-life model                                                           |
| Pinsker et al.³⁷ | USA      | CBPR                                             | Somali youth                          | To provide a culturally appropriate smoking cessation intervention                                |
| Quandt et al.³⁸  | USA      | CBPR                                             | Latino immigrants                      | To provide Lay health promoter-led pesticide safety education                                    |
| Solorio et al.³⁹ | USA      | CBPR                                             | Latino immigrant MSM                   | To provide HIV prevention outreach for men who have sex with men                                |
| Song et al.⁴⁰    | USA      | CBPR                                             | Korean-American immigrants             | To translate current dietary guidelines into a culturally tailored nutrition programme           |

Continued
Evidence of the benefits of using a participatory approach to research

The benefit most often reported among the included articles in using participatory approaches was the assertion that interventions were better tailored to the target population through involving non-academic stakeholders. However, there was greater variation and divergence in participatory approaches when considering the degree of participation of migrants. In our analysis, only 18 of the 28 included studies exhibit active participation of migrants (as the primary focus and target of the intervention) at any stage of the research process. Of these 18 studies, only 2 display evidence of active participation of migrants at all stages of the research process.

Across all 168 individual research stages analysed across the 28 studies, we recorded 46 instances of active participation of migrants; 30 instances of proxy participation; 24 instances of indirect participation and 68 instances in which there was insufficient evidence to make a determination (table 4). The active participation recorded also appears to be associated with the stage of the research. There were 7 instances of active participation during study inception; 23 during implementation; 16 during design; 23 during evaluation; and 4 during dissemination.

Evidence of the challenges of using a participatory approach to research

Multiple publications provided evidence on how iterative feedback from stakeholders during the studies could further grow partnerships, improving the recruitment of individuals to implement or take part in the intervention, and dissemination. One study also highlighted that partnerships were a feasible and appropriate means to support intervention implementation, while one set of authors reported that partnerships with non-academics can ultimately strengthen research.

Better relationships between the community and academics were cited as having the capability to enhance the familiarity and trust of individuals involved in participatory research. One study cited that increased trust had positive, or a catalyst, acting as an impartial bridge between disparate community groups. Long-lasting partnerships built over the course of participatory research studies were cited as producing a capacity-building element, increasing the health-related knowledge and resources of the community, which academics partnered with. Finally, partnerships catalysed a greater degree of understanding of a subject among communities, leading to increased self-determination and the ability to generate change of their own accord.

Participatory approaches provided benefits through the partnerships established during the research. One study reported how participatory approaches allowed for the modification of the research programme throughout conception, development and implementation. Multiple publications provided evidence on how iterative feedback from stakeholders during the study could further grow partnerships, improving the recruitment of individuals to implement or take part in the intervention, and dissemination. One study also highlighted that partnerships were a feasible and appropriate means to support intervention implementation, while one set of authors reported that partnerships with non-academics can ultimately strengthen research.

### Table 3

| Citation       | Location | Self-described participatory approach/methodology | Specific target population                          | Aim of the health intervention                  |
|----------------|----------|-----------------------------------------------|----------------------------------------------------|-------------------------------------------------|
| Suarez-Balcazar | USA      | CBPR                                          | Latino immigrant families with youth with disabilities | To provide healthy lifestyle promotion           |
| Vaughn et al   | USA      | CBPR                                          | Latino immigrants                                  | To reduce stress and increase coping skills      |
| Wieland et al  | USA      | CBPR                                          | Foreign-born                                       | To promote Tuberculosis screening               |
| Wieland et al  | USA      | CBPR                                          | Immigrants and refugees with type-2 diabetes        | To provide a digital story-telling intervention  |
| Wieland et al  | USA      | CBPR                                          | Immigrant and refugee women                        | To provide a physical activity and nutrition programme |
| Williams et al | USA      | CBPR                                          | Latino immigrants                                  | Health and safety education in construction      |

Academic stake...
in the research process and working on level-terms with migrants directly conflicted with the cultural norms of some of these individuals, who may revere authority figures, and so would in normal circumstances defer to their judgement. A further study highlighted challenges exist in bringing together differing stakeholders with varied views and experiences. In these situations, it was suggested there is no ‘one size fits all’ approach and that processes must be adapted to individual groups. Noting varied perspective, one study highlights the challenge that divergent perspectives as to what is most salient and important to address among those involved can present a challenge. The challenge (and importance) of building rapport and addressing mistrust, or even research fatigue among some groups, was also evident within publications. One set of authors identified the need for non-academic stakeholders to trust researchers alongside the need for researchers to reciprocate this trust, and prioritise the collaborative and democratic aim of participatory methods. This was perceived as challenging as it may shift the power dynamic and locus of control in the research process and working on level-terms with migrants directly conflicted with the cultural norms of some of these individuals, who may revere authority figures, and so would in normal circumstances defer to their judgement. A further study highlighted challenges exist in bringing together differing stakeholders with varied views and experiences. In these situations, it was suggested there is no ‘one size fits all’ approach and that processes must be adapted to individual groups. Noting varied perspective, one study highlights the challenge that divergent perspectives as to what is most salient and important to address among those involved can present a challenge.

Table 4 Analysis and categorisation of participatory character displayed across research stages within included studies

| Citation | Inception | Design | Implementation | Analysis | Evaluation | Dissemination |
|----------|-----------|--------|----------------|----------|------------|---------------|
| Afifi et al | o | ♦ | X | X | X | X |
| Aitaoto et al | ♦ | ♦ | ♦ | X | X | X |
| Baird et al | ♦ | X | o | X | o | X |
| Barbee et al | ♦ | ♦ | ♦ | X | X | ♦ |
| Chesla et al | X | ♦ | ♦ | X | o | X |
| Evans et al | X | X | o | X | o | X |
| Forst et al | X | ♦ | ♦ | X | ♦ | X |
| Goodkind et al | ♦ | ♦ | ♦ | ♦ | ♦ | ♦ |
| Grigg-Saito et al | ♦ | ♦ | ♦ | X | ♦ | X |
| Henderson and Slater | ♦ | o | X | X | o | X |
| Jacquez et al | ♦ | ♦ | ♦ | ♦ | ♦ | ♦ |
| Kaiser et al | ♦ | ♦ | ♦ | ♦ | ♦ | ♦ |
| Kandula et al | ♦ | ♦ | ♦ | X | ♦ | X |
| Karasz et al | ♦ | ♦ | ♦ | X | X | o |
| Kim et al | ♦ | ♦ | ♦ | X | ♦ | X |
| Lam et al | X | ♦ | ♦ | X | ♦ | X |
| Li et al | ♦ | ♦ | ♦ | X | ♦ | X |
| Nilvarangkul, McCann. 2011 | ♦ | ♦ | ♦ | X | ♦ | X |
| Pinsker et al | X | ♦ | ♦ | X | o | X |
| Quandt et al | ♦ | ♦ | ♦ | X | X | X |
| Solorio et al | ♦ | ♦ | ♦ | o | o | X |
| Song et al | ♦ | X | ♦ | X | o | X |
| Suarez-Balcazar et al | X | ♦ | ♦ | X | o | X |
| Vaughn et al | ♦ | ♦ | ♦ | X | o | ♦ |
| Wieland et al | ♦ | ♦ | ♦ | ♦ | X | X |
| Wieland et al | ♦ | ♦ | ♦ | X | X | X |
| Williams et al | ♦ | ♦ | ♦ | X | X | X |

 Active participation: Migrants appeared to be both actively involved, and wielded influence in decisions relating to the research.  
 Proxy participation: Community/third-sector organisations and/or professional services are actively involved and wield influence in decisions related to the research stage ahead (or in lieu) of migrants.  
 Indirect participation: Migrants’ involvement is restricted to activities in which they are research subjects (surveys, focus groups, interviews). No other stakeholders appear to be involved.  
 No explicit evidence: No non-academic stakeholders (migrant or otherwise) appear to be involved in this stage of the research.
away from the academics. Even when partnerships overcome challenges of culture, expectations and trust, there remain other practical challenges to operationalising these partnerships.

Challenges in ensuring equity in research understanding, and balancing the participatory nature of a project, with the standards expected by the wider scientific community were also highlighted. Furthermore, one study cited the difficulty of navigating acknowledgment and authorship of non-academics in published materials; a scenario that serves to reiterate power imbalances that can persist, in that despite being ‘equal partners’ in research, migrants may still not be equally recognised. The lack of recognition of the requirements of participatory research in traditional academic circles is also cited as a challenge, with one set of authors stating the need for managerial, institutional and funder-level buy-in and commitment regarding participatory research.

Similarly, institutional review limited participation in at least one study, preventing non-academic stakeholders’ involvement in data collection and analysis. Other practical challenges to operationalising participatory research included effective, timely communication, and the challenge of working with communities in which the dominant language of the researchers and migrant communities differ. Finally, the iterative and tailored nature of the interventions produced may also impact the generalisability of findings, while some work could seemingly omit or contradict research evidence due to localising the intervention.

**DISCUSSION**

To our knowledge, this is the first systematic review to robustly measure the application of participatory approaches and principles to health intervention research with migrants and specifically examine how core participatory principles of inclusivity and democracy are reflected in this application. While specifically focusing on research with migrants, many of the findings and the framework discussed are likely to provide insight into all practitioners of participatory research. The 28 studies included reported on a variety of developed health interventions, predominantly revolving around outreach and education. Our analysis shows that 18 of the 28 included studies actively involved migrants themselves, but only 2 studies actively involved migrants during all stages of the research process. The remaining studies either provide insufficient evidence to determine the participatory approach used or were characterised by pseudoparticipation, in which community groups/third-sector organisations were directly involved (proxy-participation), or migrants were only involved through being subjects in research activities (indirect participation).

The participatory approaches taken to develop interventions in the included studies varied. The examples that represent the most participatory approach, according to our analysis, were characterised by consistent relevant inclusivity and greater democracy, which saw co-operation between researchers and migrant individuals (whom had power on par with the researchers) (table 5). The difference between active participatory approaches and those we characterised as pseudoparticipation appear subtle when viewed from a research-centric perspective but are stark when considering a participatory perspective. First, indirect participation, in which migrants are involved in activities such as surveys or interviews designed to inform health interventions, may represent a perfectly suitable means to guide development and build evidence, but does little to distribute power in a participatory manner. The risk that research is framed as participatory while failing to develop equitable partnerships has previously been highlighted and still appears to persist.

Second, proxy participation, which may do more to uphold principles of participatory research, may still be at risk of not equitably involving the actual target population. Uncertainty persists around how to best involve non-academic stakeholders and ensure those that are involved are representative of the population of interest. While community-groups and/or professional service involvement may at times be the only, or most readily available way to represent the population of interest (due to difficulties (perceived or otherwise) in accessing, or providing access to migrants), they cannot be assumed to be representative of them. Previous research has shown that health-service users can identify different needs to service providers. Furthermore, while overall understandings of involvement processes may align, service providers may place different values on some aspects of involvement. Therefore, proxy participation could conceivably skew participatory research away from being centred on migrants’ needs.

Upholding the core principles of participatory research, in this instance, democratising research and power sharing, is particularly pertinent to partnering with migrants. Participatory research origins are firmly rooted in increasing social justice, and the promotion of doing research with, not on or about individuals and communities, particularly those that are disadvantaged. Migrant communities are often marginalised within recipient countries, and by local health systems. Our categorisations, and the challenges and considerations we highlight speak to the deeper underlying influence of power dynamics, which are present in all research and interactions and can manifest at individual, interpersonal and structural levels within participatory research.

These dynamics should not be overlooked, regardless of the perceived benefits and potential of participatory research approaches, lest participatory research unconsciously becomes a means to reinforce and further entrench power inequity individuals such as migrant participants may experience. Not only is it inappropriate
for research to perpetuate or deepen any marginalisation through failing to include migrants’ voices, insights and skills, but there are also benefits to the proper utilisation of participatory approaches to the overall research process. Included studies provide evidence of the benefits to participant recruitment, implementation, and dissemination. Researchers also highlighted that the iterative nature of participatory research allows more effective tailoring of work to the needs of migrants, through learning from and embedding migrant partners’ knowledge and experience into research. While studies we identify predominantly focus on community outreach and education within health research, participatory research could be better used across all disciplines. Similar methodology could be employed to better design pharmaceuticals, or on a larger scales, procedures and systems at a governance level.

Effectively partnering with migrants requires specific strategies to address the challenges identified in this review. Some of these strategies include early participatory involvement to guide research priorities, methodological approaches and strategies to manage ongoing relations; translating and back-translating materials; giving reassurance as to the confidentiality of involvement and respecting decisions around reporting (particularly as some partners may be undocumented migrants or have precarious legal status); using a variety of outreach and recruitment outlets, such as non-governmental organisations () and religious groups trusted by migrants and identifying opportunities for bidirectional benefits in the research, and capacity building to facilitate collaborative and democratic participation. Those partnering with migrants must demonstrate flexibility to negotiate potential power divides, and acknowledge and be considerate of residual mistrust that may exist among communities, even after researcher-community relationships appear well established. The challenges and extra consideration highlighted by this review must not be underestimated, while from a research perspective, more still needs to be done to assess the impact of participatory approaches on overall research processes and output as well as assessing whether there are distinct benefits to adopting particular participatory approaches (eg, active, pseudo). However, if research is to become more democratic, patient-centred and representative of the populations impacted by its work, traditional scientific approaches are likely to

Table 5  Descriptive tabulation of two studies classified as displaying active participation throughout all stage of the health intervention research with migrants

| Research stage | Design | Implementation | Analysis | Evaluation | Dissemination |
|----------------|--------|----------------|----------|------------|---------------|
| Inception      |        |                |          |            |               |
| Studies Goodkind et al<sup>29</sup> | Study conceived from previous relations with community groups. The present study was guided by refugees and community service providers. | The community was involved in designing interview protocols and participant recruitment procedures. | All interpreters and interviewers were refugees; procedures had been agreed during inception and design. | Refugees were involved in analysis and were actively involved in setting the agenda for what evidence was meaningful. | Refugees were involved in the dissemination and are co-authors of the research publication. |
|                |        |                |          |            |               |
| Implementation |        |                |          |            |               |
|                |        |                |          |            |               |
| Analysis       |        |                |          |            |               |
|                |        |                |          |            |               |
| Evaluation     |        |                |          |            |               |
|                |        |                |          |            |               |
| Dissemination  |        |                |          |            |               |
|                |        |                |          |            |               |

References: Goodkind et al. (2021).<sup>29</sup> Goodkind et al. (2021).<sup>17</sup>
be inadequate, with academic researchers holding the majority of power over research.58

Greater adoption of consistent and transparent reporting of participatory research is needed to support the need for more critical analysis of involvement and participatory research.17 39 While guidelines have been developed,60 they have not been widely adopted, with no material improvement in the reporting quality of published studies seen within some fields as a result of the their publication, which could be attributed to a lack of awareness of the guidelines existence.61 Tensions exist as to whether participatory research should be conceptualised and evaluated similarly to traditional research.59 62 However, we believe reporting can be sympathetic to the need to evidence impact of methods and processes on research. We propose the plain reporting of: who was involved in each element of the research; why these individuals were involved; how they were involved and who ultimately controlled decisions relating to the research. These questions should be answered by all research involving non-academic stakeholders, at every stage of the research process. The development of guidelines to support this reporting would simultaneously allow a more complete assessment of how participatory approaches impacted overall outcomes, and greater reflection and evaluation of the participatory approaches employed.62

Such guidelines and evaluative methods should incorporate and build on existing monitoring tools, such as those which specifically seek to address existing challenges around power dynamics.51 Any guidelines must also consider the distinct nature of participatory research, in that conventional evaluation is likely inappropriate with participatory research, and consequently, its evaluation may emphasise internal group evaluation, which is done for combined stakeholders in an adaptive and negotiated manner.63

Comparing our review to existing literature, there appears to be a common trend where academics and research as whole are primarily concerned with the impact or benefits of participatory approaches on research processes and outcomes, which is a valid question, but it is only encompassed in our research as a secondary aim. Nevertheless, our findings as to challenges and benefits corroborate and align with existing research that participatory approaches can provide benefits particularly to the recruitment and retention of trial participants.64–67 Challenges associated with participatory research that are previously reported and complementary to our findings often involve methodological challenges around collecting, interpreting and disseminating research.64 66

We found, similar to previous reviews, that the extent of engagement and involvement of non-academic stakeholders is highly varied, and that research that is expressly participatory is often limited.17 64–67 We also find similar trends to these previous reviews in that there is also variability in the use of naming conventions and application of reported approaches across all fields and topics of research.17 65

Our review has several limitations and caveats. First, we acknowledge the taxonomy of terminology around participatory research is not standardised and terms are used inconsistently. This is an ongoing challenge within the field, which has previously been evidenced in similar reviews.17 As such, the categorisations we have introduced and used in this review may be defined differently by others. There is also the possibility that additional publications that do not explicitly use the same language as we have are present in the literature, and that these articles may have been missed by our searches. Furthermore, whether the included studies categorised in our analysis exhibit greater or lesser participation are potentially immaterial to the quality of the research carried out, or the impact of the final intervention; quality criteria for participatory research have not been agreed on or widely adopted. The amalgamation of these limitations is that formal assessments of study quality, certainty around evidence and reporting biases are not readily applied to this systematic review as for more homogenised approaches and methods, such as clinical trials. A further consideration relates to the reporting of benefits and challenges, in that it is often unclear, which individuals or groups drove evaluations, and whether academics alone or academics and communities in partnership decided on what was reported. We have sought not only to include evidence from formal evaluation where possible but also to include evidence from articles as a whole, such as in the discussion, which could be considered reflective in nature, and potentially less rigorous on the whole. It is conceivable, given the subjective nature of some of the reported items, that differing sets of benefits and challenges would be reported dependent on the populations involved. This review represents our attempt to cast a critical lens over how the principles of participatory research are applied in practice. Our conceptual focus on migrants’ involvement is, therefore, not intended to denigrate the efforts of third-sector organisations or professional services, whose involvement we may have classified as proxy participation. Fundamentally, we believe that the examined studies are inherently more participatory than traditional research endeavours, for having even considered and attempted to involve non-academic stakeholders. We recognise the challenges associated with participatory research, and as stated, hold no assumptions about the extent of participation and its’ association with beneficial outcomes for target populations.

CONCLUSION

In conclusion, participatory approaches to developing health interventions aimed at migrants are insufficiently applied and reported. We provide evidence that the application of approaches does not fully embody core principles of participatory research, particularly relating to providing decision-making power to individuals ultimately affected by the research. Those who wish to engage in participatory research must consider the approach they
take, being cognisant and open to reflecting on questions of representation, democracy and overall power dynamics, and from this critically analysing whether their approach is sufficient to achieve high-quality participation, not just high-quality research. Crucially, guidelines for reporting of participatory research methods must be introduced. This will enable all parties, from academics to communities to better assess the participatory nature of individual research projects and is an important prerequisite to explore the overall impact of participatory research, which currently remains inadequately understood.

Twitter Alison Crawshaw @AlisonCrawshaw

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ORCID iDs
Kieran Rustage http://orcid.org/0000-0003-1599-7635
Laura Nellums http://orcid.org/0000-0002-2534-6951

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### MEDLINE Database Search Strategy (1946 – November 2020):

1. "Transients and Migrants" or Migrant.mp.
2. Migrat*.mp. [mp-title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
3. Refugee*.mp. or Refugees/.
4. Asylum-seeker*.mp.
5. Foreign*.mp.
6. Foreign-born.mp.
7. Non-native*.mp.
8. "Emigrants and Immigrants" or Immigra*.mp.
9. asylum seeker*.mp. or "Emigration and Immigration?"
10. Oversea* mp.
11. Foreign student*.mp.
12. International Student*.mp.
13. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12
14. Co-design*.mp.
15. Co-prod*.mp. [mp-title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
16. Co-creat*.mp. [mp-title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
17. Collab* design*.mp. [mp-title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
18. Collab* prod*.mp. [mp-title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
19. Collab* creat*.mp. [mp-title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
20. Community design*.mp.
21. Community prod*.mp.
22. Community creat*.mp.
23. Community-based participatory research.mp. [mp-title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
24. Participatory design*.mp.
25. Participatory action research.mp. or Community-Based Participatory Research/
26. Participatory add Research).mp. [mp-title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
27. Action Research.mp.
28. 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27
29. 13 and 28

### Embase Database Search Strategy (1974 – November 2020):

1. migrant/ or migrant worker/ or Migrant*.mp.
2. migration/ or Migrat*.mp.
3. refugee/ or Refugee*.mp.
4. asylnm seeker/ or Asylum seeker*.mp.
5. Foreign*.mp.
6. Foreign Bm*.mp.
7. Non-native*.mp.
8. immigration/ or immigrant/ or Immigra*.mp.
9. immigrnt/ or emigration/ or Emigrants/ or Emigra*.mp.
10. Oversea*.mp.
11. *Foreign Student*.mp. or foreign student/
12. International Student*.mp.
13. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12
14. Co-design*.mp.
15. Co-prod*.mp.
16. Co-creat*.mp.
17. Collab* design*.mp.
18. Collab* prod*.mp.
19. Collab* creat*.mp.
20. Community design*.mp.
21. Community prod*.mp.
22. Community creat*.mp.
23. Community-based participatory research.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
24. Action research.mp. or action research/
25. Participatory research.mp. or participatory research/
26. Participatory action research.mp.
27. (Participatory adj4 Research).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
28. 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27
29. 13 and 28

### Global Health Database Search Strategy (1920 – November 2020):

1. *Migrant*.mp.
2. Migrat*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
3. *Refugee*.mp. or refugees/
4. Asylum-seeker*.mp.
5. *Foreign*.mp.
6. *Foreign-born.mp.
7. *Non-native*.mp.
8. *Immigr*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
9. *Emigr*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
10. Oversea*.mp.
11. *Foreign Student*.mp. or foreign students.sh.
12. International Student*.mp.
13. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12
14. Co-design*.mp.
15. Co-prod*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
16. Co-creat*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
17. Collab* design*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
18. Collab* prod*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
19. Collab* creat*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
20. Community design*.mp.
21. Community prod*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
22. Community creat*.mp.
| 23. | Community-based participatory research.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word] |
| 24. | Participatory design*.mp. |
| 25. | Participatory action research.mp. |
| 26. | (Participatory adj4 Research).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word] |
| 27. | Action research.mp. |
| 28. | 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 |
| 29. | 13 and 28 |

**PsychINFO Database Search Strategy (1967 – November 2020):**

| 1. | Migrant*.mp. |
| 2. | Migrat*.mp. |
| 3. | exp REFUGEES/ or Refugee*.mp. |
| 4. | exp Asylum Seeking/ or Asylum-seeker*.mp. |
| 5. | Foreign*.mp. |
| 6. | Foreign-born.mp. |
| 7. | Non-native*.mp. |
| 8. | exp Immigration/ or Immigra*.mp. |
| 9. | Emigra*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word] |
| 10. | Oversea*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word] |
| 11. | Foreign Student*.mp. |
| 12. | exp International Students/ or International Student*.mp. |
| 13. | 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 |
| 14. | Co-design*.mp. |
| 15. | Co-prod*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word] |
| 16. | Co-creat*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word] |
| 17. | Collab* design*.mp. |
| 18. | Collab* prod*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word] |
| 19. | Collab* creat*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word] |
| 20. | Community design*.mp. |
| 21. | Community prod*.mp. |
| 22. | Community creat*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word] |
| 23. | Community-based participatory research.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word] |
| 24. | "Participatory design".mp. |
| 25. | "Participatory research".mp. |
| 26. | (Participatory adj4 Research).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word] |
| 27. | Participatory action research.mp. |
| 28. | Action research.mp. or exp Action Research/ |
| 29. | 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 |
| 30. | 13 and 29 |
Additional File 2. Summary of extracted data relating to involvement and engagement of non-academic stakeholders, and their influence over given research stages.

1. Afifi, Makhoul et al. 2011

**Aim & Target population:** Development of a mental health promotion intervention for Palestinian refugee youths.

**Inception:** Based on a previous survey of the target population which had been designed with community input

**Design:** Interview and survey of target population; formation of a community youth council with youth council representatives which agreed internal rules and implemented democratic voting re: design decisions

**Implementation:** No explicit evidence of non-academic stakeholder involvement, engagement, or influence.

**Analysis:** No explicit evidence of non-academic stakeholder involvement, engagement, or influence.

**Evaluation:** No explicit evidence of non-academic stakeholder involvement, engagement, or influence.

**Dissemination:** No explicit evidence of non-academic stakeholder involvement, engagement, or influence.

2. Aitaoto, Braun et al. 2012

**Aim & Target population:** Implementation of a cancer outreach programme for Micronesian women

**Inception:** Community group representing the target population approached researchers to highlight this topic

**Design:** Focus groups with the target population; champions from the target population were involved in literature review and aided in designing the outreach programme

**Implementation:** Target population delivered the programme as lay-educators, a decision clearly defined in the design stage by working with the champions

**Analysis:** No explicit evidence of non-academic stakeholder involvement, engagement, or influence.

**Evaluation:** No explicit evidence of non-academic stakeholder involvement, engagement, or influence; reported that the research did not ask the target population about perceptions of the intervention

**Dissemination:** No explicit evidence of non-academic stakeholder involvement, engagement, or influence.

3. Baird, Domian et al. 2015

**Aim & Target population:** To address the health challenges associated with relocation among Sudanese refugees

**Inception:** Collaborative inception between Sudanese community and researchers manifesting from previous research shared to community members, who then formed a committee which worked with the researchers; Whilst topics for intervention were collaboratively developed between researchers and the target population

**Design:** research team developed educational seminars on intervention topics.

**Implementation:** Educational seminars were delivered by the research team; target population were involved in advertising and recruiting other participants.

**Analysis:** No explicit evidence of non-academic stakeholder involvement, engagement, or influence.

**Evaluation:** Focus group discussion to evaluate the process, discuss overall findings, and plan future relationships.
### Dissemination: No explicit evidence of non-academic stakeholder involvement, engagement, or influence.

### 4. Barbee, Kobetz et al. 2010

**Aim & Target population:** To assess the acceptability of HPV self-sampling with community health workers, to detect cervical cancer among Haitian immigrant women.

**Inception:** Conceived by a campus-community partnership; the partnership is formed of community leaders and academics; community leaders are largely responsible for identifying research needs.

**Design:** Community partners responsible for defining research focus, recruitment strategies, and data collection methods; academic partners write grants applications and obtain institutional approvals.

**Implementation:** Community and academic partners contribute collectively to study implementation.

**Analysis:** No explicit evidence of non-academic stakeholder involvement, engagement, or influence.

**Evaluation:** No explicit evidence of non-academic stakeholder involvement, engagement, or influence.

**Dissemination:** Community and academic partners contribute collectively to study dissemination.

### 5. Chesla, Chun. 2013

**Aim & Target population:** Cultural adaptation of coping skills training for Chinese-American immigrants with type 2 diabetes.

**Inception:** No explicit evidence of non-academic stakeholder involvement, or influence; there is mention of a CBPR work group, and a community advisory board, but no indication these groups were involved in the inception.

**Design:** A CBPR work group composed of 10 paid staff from community agencies and academic institutions. The work group culturally adapted protocols based on clinical guidelines, clinical knowledge, and previous studies.; A community advisory board met semi-annually and provided oversight on all aspect of the CBPR activities.

**Implementation:** Work group members who were bilingual with degree level qualification in social work implemented the intervention.

**Analysis:** No explicit evidence of non-academic stakeholder involvement, engagement, or influence.

**Evaluation:** Evaluated through research/survey with participants.

**Dissemination:** No explicit evidence of non-academic stakeholder involvement, engagement, or influence.

### 6. Evans, Suggs et al. 2019

**Aim & Target population:** Promoting HIV testing uptake amongst African migrant communities.

**Inception:** No explicit evidence of non-academic stakeholder involvement, engagement, or influence.

**Design:** The design was guided by previous formative research conducted by the researchers.

**Implementation:** Participants were invited by community researchers that represented diverse African communities and genders.

**Analysis:** No explicit evidence of non-academic stakeholder involvement, engagement, or influence.

**Evaluation:** The target population provided feedback through surveys.

**Dissemination:** No explicit evidence of non-academic stakeholder involvement, engagement, or influence.
7. Forst, Ahonen et al. 2013

Aim & Target population: Increase awareness of workplace hazards and self-efficacy among foreign-born Hispanic construction workers; and expand worker centre agenda to include occupational health & safety.

Inception: No explicit evidence of non-academic stakeholder involvement, engagement, or influence.

Design: Worker centres (WC) and academics partnered to set joint goals and specific responsibilities: WC would recruit peer-educators and workers to the training, partner with implementation and evaluation; university partners assumed responsibility for subject protection, evaluation, design, and implementation.

Implementation: Worker centre staff were responsible for recruiting peer-educators to deliver the curriculum; university partners assumed responsibility for implementation.

Analysis: No explicit evidence of non-academic stakeholder involvement, engagement, or influence.

Evaluation: Iterative evaluation of the intervention with peer-educators in a democratic manner; peer-educators were able to influence study design.

Dissemination: No explicit evidence of non-academic stakeholder involvement, engagement, or influence.

8. Goodkind, Amer et al. 2017

Aim & Target population: to address social determinants of health, improve links to mental health services, and improve retention in trauma-focused treatment for Afghan, Great lakes region African, and Iraqi refugee adults.

Inception: Inception came from previous work with other community groups; present study guided by refugees, former students and community service providers.

Design: Community involved in designing the interview protocols, and participant recruitment. Implementation: target population involved in implementation; all interpreters and interviewers were refugees.

Analysis: Target population involved in analysis; active involvement in asking what evidence is meaningful.

Evaluation: CAC were involved in conversation concerning the use of CAC; have voice opinions that a community intervention paradigm should be used which the researchers appear to have heeded.

Dissemination: Target population involved in dissemination; 2nd and 8th author are refugees.

9. Grigg-Saito, Och et al.

Aim & Target population: Outreach to reduce health disparities in cardiovascular disease and diabetes among Cambodian refugees.

Inception: Coalition formed prior to this intervention to address needs of Cambodian community - resulted in the funding bid for this work; the coalition involved community leaders and elders.

Design: Collaboration amongst the coalition to develop a community action plan. Target population took part in focus groups; community forum involving target population (engagement event) took place.

Implementation: Cambodian community health programme Staff health educators go door-to-door, staff also encouraged participation from elders; Staff conducted business outreach and educational groups/worksheets; A peer-support group was established; elders council (advisory group) established at the behest of elder program participants.

Analysis: No explicit evidence of non-academic stakeholder involvement, engagement, or influence.

Evaluation: Data was reported back to staff and steering committee periodically, everyone was able to contribute to lessons learned, draw conclusions and make suggestions for improvements based on the evaluation.
| Study | Authors | Aim & Target Population | Inception | Design | Implementation | Analysis | Evaluation | Dissemination |
|-------|---------|-------------------------|-----------|--------|----------------|----------|------------|--------------|
| 10.   | Henderson, Slater | Nutrition information for newly arrived immigrants | based on previous community-based participatory research | Community consultation | No explicit evidence of non-academic stakeholder involvement, engagement, or influence. | No explicit evidence of non-academic stakeholder involvement, engagement, or influence. | community consultation on evaluation | No explicit evidence of non-academic stakeholder involvement, engagement, or influence. |
| 11.   | Jacquez, Vaughn et al. 2019 | Implementation of a stress reduction intervention for latino immigrants. | Manifested from a previous relationship with latinos unidos por la salud to promote health and healthcare for the local latino community; community members applied and were selected as co-researchers | Community group co-researchers worked with academic partners to identify primary outcomes, and that health-worker delivered strategies were the preferred intervention option. | Co-researchers recruited and worked with participants to identify strategies with participants. | co-researchers and academic partners identified the primary outcomes | Academic and community partners shared decision-making in all aspects of the research process, including evaluation. | Academic and community partners shared decision-making in all aspects of the research process, including dissemination. |
| 12.   | Kaiser, Martinez et al. 2015 | Adaptation of a culturally relevant nutrition and exercise program for Mexican immigrant parents with young children | Researchers conceived through reviewing literature and involving the target population in focus groups to assess their interpretation and prioritisation of key childhood obesity messages. | Researchers performed a literature search and involved the target population in focus groups; the researchers presented the plans for a nutrition program to a local advisory committee whom convened quarterly and gave advice on how to deal with specific issues | A local educator with experience of family counselling was hired to deliver the intervention | No explicit evidence of non-academic stakeholder involvement, engagement, or influence. | pilot testing with a subsection of families who were invited to give feedback; educator and specialist would evaluate intervention events after each one for changes; participants were invited to focus groups to report back on the intervention. | No explicit evidence of non-academic stakeholder involvement, engagement, or influence. |
| 13.   | Kandula, Dave et al. 2016 | | | | | | | |
| **Aim & Target population:** Exercise intervention for south-asian mother with risk factors for diabetes |
|---|
| **Inception:** Local community group and researchers collaboratively chose the focus of the research |
| **Design:** Community partner and academics adapted and applied evidence-based behaviour change principles in partnership; a memorandum of understanding was agreed by the partners: The community group was involved in design, implementation, recruitment and evaluation. |
| **Implementation:** Community partner was responsible for recruitment and outreach |
| **Analysis:** No explicit evidence of non-academic stakeholder involvement, engagement, or influence. |
| **Evaluation:** The community partner was involved in evaluation; participants were involved in the evaluation of the intervention through qualitative interviews. |
| **Dissemination:** No explicit evidence of non-academic stakeholder involvement, engagement, or influence. |

14. Karasz, Raghavan et al. 2015

| **Aim & Target population:** Development of an asset-building mental health intervention for Bangladeshi immigrant women |
|---|
| **Inception:** Outgrowth from previous partnerships; the development involved local physicians, a health advocate and researchers. |
| **Design:** The target population were included as part of the intervention design group |
| **Implementation:** No explicit evidence of non-academic stakeholder involvement, engagement, or influence. |
| **Analysis:** No explicit evidence of non-academic stakeholder involvement, engagement, or influence. |
| **Evaluation:** No explicit evidence of non-academic stakeholder involvement, engagement, or influence; target population were involved in the evaluation through research methods. |
| **Dissemination:** No explicit evidence of non-academic stakeholder involvement, engagement, or influence. |

15. Kim, Koniak-Griffin et al. 2004

| **Aim & Target population:** Cardiovascular health promotion among latino immigrants |
|---|
| **Inception:** Collaboration with local department of health and nurses |
| **Design:** Local department of health refined area for targeting; 2 community based organizations and the formation of an advisory board (including migrants) was instrumental in tailoring the study to the target community (e.g. changing name from lay health advisor to promotoras de salud). |
| **Implementation:** Lay health advisors were recruited and trained, by the local department of health, to deliver the intervention |
| **Analysis:** No explicit evidence of non-academic stakeholder involvement, engagement, or influence. |
| **Evaluation:** Feedback from the local health department, community advisory boards and lay health educators allowed flexible iteration of the intervention |
| **Dissemination:** No explicit evidence of non-academic stakeholder involvement, engagement, or influence. |

16. Lam, McPhee et al. 2003

| **Aim & Target population:** Increase pap/cervical cancer screening among Vietnamese-american women |
|---|
| Inception | Design | Implementation | Analysis | Evaluation | Dissemination |
|-----------|--------|----------------|----------|------------|---------------|
| No explicit evidence of non-academic stakeholder involvement, engagement, or influence. | Shared with the REACH (community) coalition (who had overall power); community forum was held with 200 Vietnamese-American women and their families to discuss cervical cancer and brainstorm strategies to increase screening (the REACH coalition then took findings to generate the intervention); The results were shared with a second community forum, with feedback used to finalise the intervention (by the coalition). | The lay health worker campaign was community-led; Lay health educators were the target population; the community coalition was involved in implementing a media campaign. | No explicit evidence of non-academic stakeholder involvement, engagement, or influence; institutional review board deemed partners could not collect data. | Media campaign was evaluated at a community forum in which community members opinions were sought through questionnaires and discussions. The REACH coalition retained the power to effect changes; lay health worker opinion was solicited through research methods/questionnaires; No evidence of individual health workers being able to influence intervention in progress. | No explicit evidence of non-academic stakeholder involvement, engagement, or influence. |

17. Li, Yeh et al. 2019

**Aim & Target population:** Colorectal cancer prevention among Chinese-americans

**Inception:** Researchers and leaders from community groups agreed to promote colorectal cancer prevention in Chinese-americans.

**Design:** Designed between the researchers with feedback from the community group; Researcher carried out a literature review with feedback from community partner, research with the actual community in the form of qualitative interviews was conducted to inform the design; Appears community group did have influence, changed from a web-based idea due to community group input.

**Implementation:** Delivered by the researchers

**Analysis:** No explicit evidence of non-academic stakeholder involvement, engagement, or influence.

**Evaluation:** The community group members were involved in filling out surveys as part of the evaluation

**Dissemination:** No explicit evidence of non-academic stakeholder involvement, engagement, or influence.

18. Nilvarangkul, McCann et al. 2011

**Aim & Target population:** Enhancing health-related quality of life for Laotian migrants

**Inception:** Conceived by researchers with a broad action plan developed in collaboration with the target population

**Design:** The target population were involved in interviews used to shape the intervention; meetings were held with community workers and stakeholders to create action plans

**Implementation:** Community workers, stakeholders and researchers implemented the action plan

**Analysis:** No explicit evidence of non-academic stakeholder involvement, engagement, or influence.

**Evaluation:** Meetings were held with community workers and stakeholders as part of the formative evaluation; intervention participants were followed up via qualitative data collection

**Dissemination:** No explicit evidence of non-academic stakeholder involvement, engagement, or influence.

19. Pinsker, Call et al. 2017

**Aim & Target population:** Tobacco use prevention videos for Somali youth
### 20. Quandt, Grzywacz et al. 2013

**Aim & Target population:** Pesticide safety intervention for migrant farmworkers

**Inception:** Based on an existing relationship between the university and community partners

**Design:** Based on an existing partnership; not immediately obvious how target population and non-academic stakeholders were involved.

**Implementation:** Implemented by the community partners; lay health promoters were recruited from within the community and trained by the community partner

**Analysis:** No explicit evidence of non-academic stakeholder involvement, engagement, or influence.

**Evaluation:** No explicit evidence of non-academic stakeholder involvement, engagement, or influence.

**Dissemination:** No explicit evidence of non-academic stakeholder involvement, engagement, or influence.

### 21. Solorio, Norton-Shelpuk et al. 2014

**Aim & Target population:** HIV prevention messages for young Latino immigrant men who have sex with men

**Inception:** There is a previous community-university relationship, uncertain as to where the inception for the project came.

**Design:** Storyboard/intervention was put before the target group in focus groups, Latino MSM were hired to facilitate the focus groups and help interpret the findings

**Implementation:** Intervention was actioned by an external digital marketing/media team who used the design focus groups to develop the campaign

**Analysis:** Latino MSM were hired to help interpret the findings

**Evaluation:** The target population were involved in focus groups to assess their comprehension of the intervention

**Dissemination:** No explicit evidence of non-academic stakeholder involvement, engagement, or influence.

### 22. Song, Han et al. 2010

**Aim & Target population:** Translating dietary guidelines into a culturally tailored nutrition education program for Korean-American immigrants with type 2 diabetes

**Inception:** There is a previous relationship between researchers and community, but no clear link as to how this explicitly influenced inception

**Design:** No explicit evidence of non-academic stakeholder involvement, engagement, or influence.

**Implementation:** No explicit evidence of non-academic stakeholder involvement, engagement, or influence; appears the education program was delivered by nurses and dieticians

**Analysis:** No explicit evidence of non-academic stakeholder involvement, engagement, or influence.
|   |   |
|---|---|
| **Evaluation:** Target population were involved in evaluating the interventions’ acceptability  
**Dissemination:** No explicit evidence of non-academic stakeholder involvement, engagement, or influence. |
| **23. Suarez-Balcazar, Early et al. 2018** |
| **Aim & Target population:** Healthy lifestyle promotion among Latino immigrant families with youth with disabilities  
**Inception:** No explicit evidence of non-academic stakeholder involvement, engagement, or influence.  
**Design:** Focus groups with the target population; interviews and conversations with community stakeholders and agency personnel; research built on by collaboration with mothers and staff from community organisations  
**Implementation:** Delivered by bilingual occupational therapy and nutrition students; co-facilitated by mothers who presented Zumba sessions and prepared healthy snacks.  
**Analysis:** No explicit evidence of non-academic stakeholder involvement, engagement, or influence.  
**Evaluation:** Evaluated through focus groups at the end of the intervention  
**Dissemination:** No explicit evidence of non-academic stakeholder involvement, engagement, or influence. |
| **24. Vaughn & Jacquez. 2019** |
| **Aim & Target population:** Stress and coping intervention for Latino immigrants  
**Inception:** There are existing relations between the researchers and community; migrant community members were selected to be co-researcher  
**Design:** Design input came from researchers and community co-researchers  
**Implementation:** Community co-researchers implemented the intervention  
**Analysis:** Co-researchers provided evaluation through interviews with the researchers  
**Dissemination:** No clear evidence, though does mention co-researchers want to be involved in dissemination including publications and presentations |
| **25. Wieland, Nigon. 2019** |
| **Aim & Target population:** Tuberculosis screening for migrant adults  
**Inception:** Conceived and initiated by a community organisation  
**Design:** Academic and non-academic community organisation co-designed the intervention; not sure of the involvement of the target population  
**Implementation:** Intervention was implemented by community organisation staff, along with clinical/nursing staff and students  
**Analysis:** Evidence was collected and analysed by local health practitioners  
**Evaluation:** No explicit evidence of non-academic stakeholder involvement, engagement, or influence.  
**Dissemination:** No explicit evidence of non-academic stakeholder involvement, engagement, or influence. |
| **26. Wieland, Njeru et al. 2017** |
| **Aim & Target population:** Digital storytelling intervention for immigrants and refugees with diabetes  
**Inception:** Impetus came from an existing researcher-community partnership; diabetes co-agreed as an area for research and intervention  
**Design:** survey developed by community-academic partnership to understand target population, attitudes and behaviours in T2DM; focus groups were conducted to further inform intervention |
content and to identify gifted storytellers; storytellers were recruited by community partners and their stories were captured, recorded and edited to derive the final intervention product.

Implementation: No explicit evidence of non-academic stakeholder involvement, engagement, or influence.

Analysis: No explicit evidence of non-academic stakeholder involvement, engagement, or influence.

Evaluation: participants completed follow-up surveys

Dissemination: No explicit evidence of non-academic stakeholder involvement, engagement, or influence.

27. Wieland, Wies. 2012

Aim & Target population: Physical activity and nutrition program for immigrant and refugee women

Inception: Conceived from a community-academic partnership with long-standing ties; formalised to use CBPR to improve migrant health

Design: Exercise programme piloted; refugee and immigrant women were included as focus group participants

Implementation: Implemented by researchers and community organisation; community organisation recruited women to the programme; community organisation provided facilities

Analysis: No explicit evidence of non-academic stakeholder involvement, engagement, or influence.

Evaluation: No explicit evidence of non-academic stakeholder involvement, engagement, or influence.

Dissemination: No explicit evidence of non-academic stakeholder involvement, engagement, or influence.

28. Williams, Ochsner et al. 2010

Aim & Target population: Health and safety training for Latino day laborers

Inception: Inception appears to come from advocacy/community groups

Design: Focus groups held with the target population to identify typical exposures and situations to be addressed by peer trainers; curriculum was revised with feedback from these peer trainers

Implementation: Delivered by peer-trainers

Analysis: No explicit evidence of non-academic stakeholder involvement, engagement, or influence.

Evaluation: Evaluated through focus group discussions and pre & post-training surveys;

Dissemination: No explicit evidence of non-academic stakeholder involvement, engagement, or influence.