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Engaging veterans in the research process: a practical guide

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Aims: Provide guidance for engaging military veterans in various research teams to help overcome veterans' lack of trust in research. **Methods:** We draw from our combined experience to present four case studies of veteran research on sensitive topics to illustrate successful engagement with veterans. **Results:** For each case example, we describe veterans' contributions at different phases of research. We then share practical guidance for realizing benefits and overcoming challenges of engaging veterans in research at each phase. In our experience, successful engagement has built trust by aligning research with participants' own experience as veterans. **Conclusion:** Investigators wishing to engage veterans in research may benefit from the lessons presented through these case studies.

Tweetable abstract: Want to engage veterans in the research process? Build trust. This cross USA & UK case study analysis shows how.

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Military veterans are recognized as a marginalized, multifaceted population with a distinct culture [1], and they frequently have unique health and social care needs. Many military veterans make the transition from military to civilian life without difficulty; however, there remains a proportion of veterans who have experienced multiple and complex health, financial and social needs. The complex problems tend to exacerbate each other and deepen over time if appropriate support is not provided – which is in turn made more difficult by the well-documented lack of trust by veterans in the social and healthcare systems that are designed to support them [2–4].

Research can help health and social care services understand and meet these needs better, particularly when the research process engages military veterans themselves [5]. Yet, the veteran population may experience barriers to engage in research similar to those encountered in accessing social and healthcare support. This includes a general mistrust of the research process [2,6,7] due, for example, to a history of tests conducted on military personnel without their specific consent [8]. Offsetting these potential barriers can be a firm sense of comradery and loyalty, and strong bonds formed by shared experiences [7], which can create a distinct subculture among veterans and active military/serving personnel. Developing best practices in community-engaged research with veterans has the potential to draw from these shared experiences to overcome barriers, build on facilitators, and improve research processes and outcomes.

The concept of community involvement in research is not new, particularly in a public health setting. 'Peer-led' or 'respondent-driven' sampling techniques have been used extensively as a method to recruit from hard to reach or seldom heard from populations. Previous research on the effectiveness of peer-led or respondent-driven techniques has focused on recruiting participants for large scale quantitative studies – such as clinical trials and intervention research [9,10]. Thus, much of the existing literature focuses on recommendations for increasing trust

and building on comradery to enhance recruitment and ensure veteran research participation [7,8,11]. Littman *et al.* [7], for example, found that emphasizing altruism and the obligation to help other veterans was a key factor in encouraging participation among Iraq- and Afghanistan-deployed US veterans. Braun *et al.* [11] recommends using trained veteran peer research advisors to overcome challenges related to recruiting women veterans. And Flynn *et al.* [8] determined, based on extensive veterans' dialogue sessions, that veterans prefer both being recruited by other veterans and having veterans included on the research team, among other recommendations. As stated, this prior work focuses more on involvement than engagement.

While involvement and engagement may overlap conceptually and practically, an exclusive focus only on the involvement of community members may result in limitations to community engagement throughout the comprehensive process of designing research questions, seeking funding, designing methodology, conducting the data collection, participating in the analysis and dissemination. In recent years, researchers have taken this into account, and several papers have recently been published reflecting the potential for engaging veterans and other stakeholders in the full spectrum of research-related activities [12–15].

In this paper, we aim to build on this expanding focus, from veteran involvement to veteran engagement, by sharing what we have learned from our combined experience in engaging veterans and their family members in the research process. We demonstrate this through case study examples, describing the benefits and challenges of engaging veterans as part of the research team. We also offer guidance for those wishing to include veterans in future research studies.

As described, our research covered sensitive topics related to military service that required trust on the part of research participants, and engaging veterans in the research process was essential to building this trust. While most participants saw the veteran peers serving on these studies as study representatives at the time of data collection, veteran engagement in our research went beyond this level of involvement. Veterans helped our research teams to better understand the population's needs and to take sensitivities into account in study design, data collection and dissemination. At times, they also facilitated the translation of the research into practice and set the agenda for future studies, thus ensuring that the research data directly served the community from its origin.

Methods

We draw upon our research experience to present four case studies that illustrate the range of successful engagement with veterans and members of the armed forces community. We, the authors, represent two very different institutions, in terms of both service type and geography: the United States Department of Veterans Affairs (VA) and Northumbria University Newcastle, United Kingdom. Nonetheless, our common commitment to veteran engagement in research has led to similar experiences.

To develop the case examples, the authors met and decided upon examples of their research involving veterans that could serve as exemplars. The author representative(s) from each respective study team then developed an initial summary of their study. Led by the first author, all authors then engaged in an iterative process in which the case study descriptions were refined, and, through a series of discussions, the emergent themes were developed. After this, the first and senior authors drafted initial lessons learned (conclusions) which were then refined by the full author team. All discrepancies were resolved through discussion, resulting in the case studies and themes presented below. Studies reviewed in this article were funded by research grants, obtained appropriate institutional review board approval, and, when applicable, obtained informed consent from human subjects.

Each example case describes how we have benefited from the contribution of veterans and their immediate family members as 'experts by experience', meaning as experts through the personal experiences of serving in or being a family member of someone in the armed forces. This paper focuses on the common themes among these research studies of (1) the contribution to academic research by those who have lived through transition from the armed forces back into civilian society, (2) how this co-production enriched the research by contributing multiple perspectives, and (3) how this type of research relationship can build trust and encourage engagement of study participants.

The four case studies describe working with veteran stakeholders and/or their family members from the time that a study is first being framed through dissemination of findings, and then completing the cycle by translating research into practice and setting the agenda for future research (Figure 1). For the reader's ease of reference, we divided this work by commonly used phases along the research cycle [16–18]:

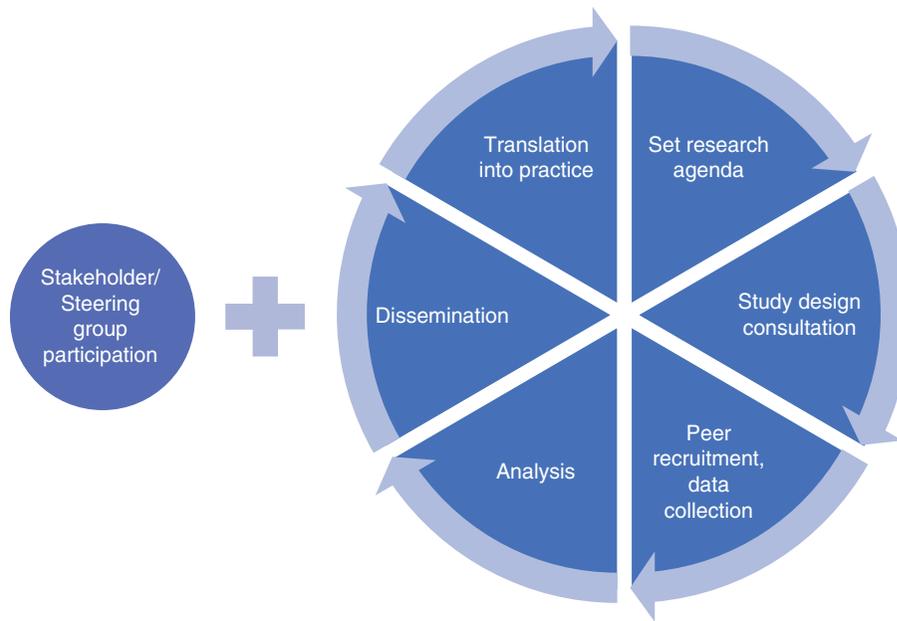


Figure 1. Phases along research cycle.

- Stakeholder/steering group participation.** As stakeholders on the research team, a small group of veterans/family members meets regularly throughout the course of the study. The steering group may be comprised solely of veterans/family members or a combination of researchers, peers, and other stakeholders. The stakeholders contribute their expertise and represent study participants' interests, giving feedback and voicing concerns as the study progresses.
- Set research agenda.** Veterans, as members of the community being served, recognize evidence gaps and identify research needs. Either informally in conversation or formally – e.g., as part of a stakeholder group – they help to focus and prioritise future research. In this way the direction of research follows the needs of the community.
- Study design consultation.** Study design consultation is a broad area of veteran involvement that addresses questions of study feasibility and acceptability, such as approach (e.g., participatory action, qualitative or quantitative); methods (e.g., use of photovoice, focus groups); or materials design (e.g., recruiting materials, interview guides, survey instruments). A veteran's ability to point out flawed assumptions and assistance with addressing sensitive issues can be a key contribution to successful study design. This may happen through consultation with individual veterans or as part of a stakeholder/steering group.
- Peer recruitment and data collection.** Peer recruitment involves identifying, engaging, and consenting research study participants, as well as contributing to retention by keeping participants engaged over time. Data collection includes, among other possibilities, conducting one-on-one interviews. Through data collection, frontline peer recruiters can develop their common bond to directly build and maintain trust.
- Analysis.** Drawing from their experiential expertise on the topic and with some training, veterans can participate in qualitative analysis through data coding and theme-building, and analytic themes can be checked against their lived experience.
- Dissemination.** Veterans and/or their family members participate in disseminating findings in traditional ways such as by contributing to written study reports and presenting at formal meetings and conferences. They can also help identify channels for presenting findings to the populations from which the study data was drawn.
- Translation into practice.** Veterans and family members who have served on the research team – e.g., as peer recruiters – build on their knowledge, experience, and social connections to continue their work after the study is completed.

In the sections that follow, we first describe each case study, including its context, research objectives, and brief methods as each of these pertains to veteran engagement at the various research phases listed earlier (Table 1). We then use these case studies to illustrate the benefits and challenges of involving veteran and family member

Table 1. Case study overview of veteran/family member involvement and benefits of and challenges to veteran/family member participation.

| Case study | Veteran /family member involvement | Benefits of participation | Challenges to participation |
|--|--|---|--|
| Case study A: in-depth interviews with veterans who have experienced limb loss | <ul style="list-style-type: none"> • Study design consultation • Research tool development • Peer recruitment • Steering Group members | <ul style="list-style-type: none"> • Enhanced study recruitment • Presence on research team addressed power imbalance, gave veterans a voice; may have reduced bias | <ul style="list-style-type: none"> • Geographical distance from rest of research team • Communication issues within meetings |
| Case study B: examining the process of casualty notification of war widows in the UK | <ul style="list-style-type: none"> • Set research agenda • Study design consultation • Peer recruitment • Data collection • Analysis • Dissemination | <ul style="list-style-type: none"> • Research tool designed based on family member experience • Increased trust, facilitating discussion of sensitive subject • Broader audience for dissemination | None identified. |
| Case study C: using smartphone data to understand residential transition patterns in veterans with histories of homelessness and substance abuse | <ul style="list-style-type: none"> • Study design consultation • Letter of support to grant funders • Research tool development • Stakeholder Council participation | <ul style="list-style-type: none"> • Improved research protocol through potential concerns being identified ahead of time • Favorable grant review comments regarding veteran involvement in study design | <ul style="list-style-type: none"> • Ongoing mental, behavioral, and physical health issues affect ongoing participation in consulting • Changes in access to cell phone, email and physical address complicate engagement |
| Case study D: interviews with veterans seeking to engage in alcohol misuse treatment programmes | <ul style="list-style-type: none"> • Study design consultation • Peer recruitment • Translation into practice | <ul style="list-style-type: none"> • Enabled recruitment from a broader population • Peer became member of ongoing programme team after study | None identified. |

stakeholders at each phase of research and offer practical guidance for readers who are considering involving veterans, family members, and other stakeholders in future research (Table 2).

Case study results

Case study A: veterans who have experienced limb loss

This study explored the future physical, psychological and social needs of ex-servicemen and women experiencing limb-loss by investigating older veterans' individual narratives. The research project recruited participants through the British Limbless Ex-Servicemen's Association (BLESMA – <https://blesma.org/>), a national UK charity dedicated to offering support to veterans who have lost limbs. The study took place over an eight-month period between 2016 and 2017 and employed a multiple method convergent design. The design encompassed Narrative Inquiry and Applied Policy Research. Specific study details are described elsewhere [19–21]. For this study, veterans were actively involved as researchers within the research team, contributing to the design of the research proposal as well as the development of the research tools. Veterans also supported and coordinated recruitment into the study.

One of the dilemmas with any in-depth qualitative research such as this is the emotional investment required by the participant to recall and tell their story. The data collection for the research study consisted of in-depth interviews with 32 veterans who experienced limb loss. Life histories were collected with up to three interviews per participant. As a result, there were close to 100 hours of in-depth, narrative data collected. The extent of data collection presented its own challenges as not only finding and engaging participants from this community was difficult, but also keeping them engaged over time to facilitate complete data collection proved challenging.

To address potential issues, the research team recruited two BLESMA members during the planning stage to help develop the research questions and prepare the recruitment material. Following this planning phase, the two veterans (both active members of the BLESMA charity) were appointed as peer recruiters. The two peer recruiters were paid members of staff and were recruited because they already had an existing relationship with some of the potential participants through their work with BLESMA (both were members of BLESMA). This enabled them to quickly and easily establish a rapport with potential participants and to gauge the level of interest. They also offered support to the veterans who agreed to participate, throughout the duration of the study.

The peer recruiters were involved in the study as members of the study Steering Group. The Steering Group was set up prior to the project official start date and met for the duration of the project to examine progress with the milestones and address any challenges and to support the peer recruiters. Members included principal investigators, senior research assistants, BLESMA chief executive, peer recruiters, and an independent chair (members met monthly), and worked alongside the academic research team who offered support to them with regard to the research process and progress from beginning to end, including dissemination and preparation of the project

Table 2. Involving veteran and family member stakeholders at multiple phases of research.

| Research phase | Involvement | Benefits | Challenges | Guidance |
|--|---|--|--|---|
| (1) Stakeholder/steering group participation | Veterans meet regularly to contribute their expertise and represent study participants' interests | <ul style="list-style-type: none"> Ensuring sensitivity and ethical compliance Enhancing a positive experience for participants Contributing viewpoint to research | <ul style="list-style-type: none"> Inadvertently creating barriers to participation, such as lack of communication Recognizing logistical challenges veterans may face | <ul style="list-style-type: none"> Co-create meeting guidelines, other expectations in advance Use flexibility to creatively problem-solve logistical challenges |
| (2) Set research agenda | Veterans recognize evidence gap and identify research need | <ul style="list-style-type: none"> Addressing community needs Ensuring acceptance of research by community | <ul style="list-style-type: none"> Missed opportunities to communicate needs Perceived or actual power imbalances | <ul style="list-style-type: none"> Maintain frequent contact with veterans, community organizations Build relationships based on collaboration |
| (3) Study design consultation | Veterans advise on issues that affect study feasibility and acceptability | <ul style="list-style-type: none"> Identifying solutions to overcome research barriers Contributing information to respond to peer reviewers Demonstrating support for funding | <ul style="list-style-type: none"> Identifying and enrolling veterans early in process Integrating veterans into the research team | <ul style="list-style-type: none"> Maintain a database of veterans available to consult Train investigators Check in with veterans frequently prior to funding |
| (4) Peer recruitment and data collection | Veterans identify, engage, and consent study participants, then keep them engaged over time; veterans collect study data through, e.g., one-on-one interviews | <ul style="list-style-type: none"> Building participant trust and contributing to sense that research is worthwhile Improving retention Reducing researcher bias and improving data quality | <ul style="list-style-type: none"> Ensuring regulatory compliance for veterans as research team members | <ul style="list-style-type: none"> Allow time and resources for training, other regulatory requirements |
| (5) Analysis | Veterans contribute to data coding and theme building, confirm analytic themes | <ul style="list-style-type: none"> Adding authenticity to findings Translating findings to program activities | <ul style="list-style-type: none"> Lacking awareness that involvement at this level is possible | <ul style="list-style-type: none"> Invite veterans already involved in recruitment, data collection to contribute to analysis Start with more limited analysis activities, such as comparing themes to veteran's own experience |
| (6) Dissemination | Veterans identify communication channels and contribute to reports, papers, and presentations | <ul style="list-style-type: none"> Spreading research benefits beyond the research community Making dissemination more impactful | <ul style="list-style-type: none"> Addressing cost of attending events Encountering discomfort with public speaking | <ul style="list-style-type: none"> Select appropriate forum Support veterans in choosing, preparing for their level of involvement Have a backup plan |
| (7) Translation into practice | Veteran peer recruiter for research continues as peer support worker for intervention | <ul style="list-style-type: none"> Peer research is model for intervention Veteran social connections made through research facilitate support role | <ul style="list-style-type: none"> Identifying continued funding for intervention | <ul style="list-style-type: none"> Ensure that peer recruiter has appropriate type and level of shared military experience to leverage beyond research |

report. It was important that peer recruiters were empowered to have a voice within the Steering Group together with support provided by the research team throughout the duration of the study.

The role of the peer recruiters was to support identification of eligible participants and to help them make an informed decision about participation. In addition, the peer recruiters engaged early in the study to provide feedback on data collection and analysis. This approach had the potential to empower participants by giving them a voice and minimizing a power imbalance between the researcher and participant, also perhaps reducing bias and enhancing the quality of the data collected. Mutual understanding of the research topic and shared language also helped to build rapport and support effective communication.

The peer recruiters also took part in a follow up case study to explore and document their own personal development and experience of their involvement throughout the research project. The peer-informed approach to the study that was presented at the 3rd World Conference on Qualitative Research (Lisbon, Portugal) and published in the conference proceedings [22]. The case study outlined the central role of the peer recruiters to support identification of eligible participants and to help them make an informed decision about participation. The peer recruiters' involvement in the project was costed in the project and they were paid for their time. From these case studies, it was clear that the peer researchers felt recruitment benefitted from their shared understanding of the participants' unique needs, as well as their understanding of barriers typically preventing engagement in research. The peer researchers also discussed their own involvement in the study and felt a sense of enjoyment and satisfaction of helping others, as well as feeling as though their experiences positively impacted their own work. However, there were also learning points to be considered when carrying out future research. Namely, the peer researchers felt that

geographical separation from the wider research team and communication issues within meetings were problematic and impeded on their participation within the wider research study.

Case study B: casualty notification of war widows in the UK ('knock on the door')

This study explored how the casualty notification is undertaken when reporting the death of a member of the UK Armed Forces, and the impact of this on the family and/or significant other. Receiving the news is widely referred to among the Armed Forces population as the 'knock on the door'. The study used an exploratory sequential mixed method design. The study took place between April 2019 and March 2021. Specific study details are described elsewhere [23]. For this study, spouses of veterans were involved in multiple phases of the research cycle (study design consultation, peer recruitment, data collection, analysis, and dissemination); stakeholder/steering group participation, which was not a part of this study.

The need for this research came directly from the community itself, through conversation with the chairperson of the War Widows' Association (WWA and, subsequently, the peer researcher) and a member of the Northern Hub for Veterans and Military Families Research. From this conversation it was evident that there was a complete lack of evidence examining the process and impact of casualty notification. This was pivotal to the research we carried out, as it evolved directly from the community on which it is focused. As such, the study was supported by the WWA. The WWA is unique and recognised as the United Kingdom's leading representative organization for War Widows, irrespective of rank or service (Royal Navy, RAF, and Army).

The focus of this research was extremely sensitive. Because of this, input from a war widow as a peer researcher was paramount throughout this project. The peer researcher supported the funding application, was named on the bid, and was paid for the time spent on this project. The peer researcher also collaborated in designing the interview schedule and survey. This was fundamental to creating research tools bound in experience but done so sensitively, using appropriate phrasing and terminology. Bringing a peer-led perspective to the development of the first iterations of the questions for both research tools also helped to identify what questions were important to answer.

The greatest challenge in undertaking this research was access to this hard-to-reach and potentially vulnerable community. The recruitment strategy built on the relationships that WWA has with the wider military bereaved community to develop a connective network that ensured that this study acquired a holistic understanding of how all members of the family are affected by the 'knock on the door'. The peer researcher was fundamental to this recruitment process, and feedback from participants strongly suggests that involvement from the WWA supported their decision to participate – they did not feel that research was being 'done to them' but 'done with them', and with purpose. Having a member of the War Widows' Association as part of the research team proved crucial within a challenging timeframe.

The peer researcher was provided informal training in carrying out semi-structured interviews, and they shadowed the research team before conducting their own interviews. The peer researcher was also involved in the data analysis process. Three members of the research team collaboratively coded the data and generated initial themes. A data analysis workshop was then held with the peer researcher, and a joint discussion was held examining the coding, themes, and abstracting the data further. Whilst quantitative analysis of survey data was carried out by members of the research team, who had statistical expertise, the peer researcher was informed about this analysis and the survey's outcomes at all stages.

Working alongside the peer researcher was fundamental in ensuring our research findings would be heard by the community on which it involves. The peer researcher supported the writing of the study report and is an author on a published paper, contributing to the final edits and acting as an advisor based on her role in the research team and as an 'expert by experience'. Furthermore, the peer researcher invited two members of the research team to attend a formal meeting and dinner with WWA and present some initial findings and discussion points. This dissemination is ongoing.

Case study C: veterans with histories of homelessness and substance abuse ('journeys')

This study's aims were threefold: to use ethnographic methods to assess the feasibility of smartphone data collection from US military veterans experiencing homelessness, use the findings from that phase to build a mobile application, and conduct a demonstration of mobile data collection methods that integrate quantitative data sources like global positioning system (GPS) and electronic momentary assessment (EMA) with qualitative data to identify distinct patterns of residential transitions. The study is a convergent mixed methods design. Data collection began in

November 2020 and is ongoing. The study follows work from other studies using GPS [24], EMA [25], and technology use among US veterans experiencing homelessness [26,27]. For this study, veterans have been primarily involved in the study design process, with their role forecasted to expand as the initial data collection phase shifts into analysis focused on mobile application development.

Three veteran consultants were recruited who had a history of homelessness, were currently experiencing homelessness, were engaged in behavioral and mental health treatment, or had a combination of those categories. To ensure the one consultant who was experiencing ongoing homelessness could participate without the added barriers of travel or video conferencing, study team members worked in-person with the veteran at a location of the veteran's choosing. Since the veteran was in stable shelter housing, no other issues prevented them from participating. For consultants with past histories of homelessness, study team members met in-person at the Bedford VA Healthcare System or remotely via teleconferencing platforms to complete their consultations, whichever the veteran preferred. The consultants were invited to participate in the study as part of a veteran consultant network, a panel of veterans screened for their research interests and assigned to studies throughout the VA Bedford and Boston (Massachusetts) Healthcare Systems. The veteran consultants were invited to participate early in the grant writing process, prior to the first submission of the grant to the funder. They wrote a letter of support for the grant highlighting the viability and importance of the proposed work, which was used in all three rounds of submission necessary to achieve funding.

In response to shortcomings highlighted in the first-round grant submission, the veteran consultants provided feedback on the general aims of the project, drafted materials, and offered reflections from personal experience on what issues may be central to the success of the grant. In this final step, the consultants raised issues concerning the possible viability of mobile data collection methods, technology use, and other topics that they thought had been overlooked. Issues raised included phone theft, phone charging, attitudes toward surveillance by the mobile application, and phone sharing. When the grant was reviewed the second time, reviewers also raised similar concerns about loss of phones, theft, fidelity of data, and realistic uses of the phones by veteran participants. The research team was therefore able to leverage the data collected from the veteran consultants to directly respond to reviewer concerns, a fact that reviewers noted positively in later rounds of the grant review process.

Additionally, in preparation for the initial grant submission, the research team members conducted focus groups with veterans living in homeless shelter partner sites. These focus groups used the concerns and ideas brought up by the veteran consultants as guides and generated aggregate information that the team added to the grant submission. The focus groups also brought awareness to the team of several different considerations relevant to the study population, including types of phones being used, phone service carriers, and level of comfort with the idea of phones being used for research. Topics around notions of generational differences related to phone use, application use, and feelings and knowledge about the implications of GPS tracking were also discussed. These findings, again, directly correlated with later grant reviewer concerns, and enabled direct responses to these concerns.

Veteran consultants also reviewed pilot interview guides to identify any gaps in questioning, assumptions, and places for rewording and addition within the documents. In these conversations the veteran consultants organically offered feedback on how best to collect data about homeless participants' living arrangements, provided insight into how veterans talk and what they say about their experiences of homelessness, and discussed possible roadblocks related to data collection on the topic of mental health and substance use.

For the study, the veteran consultants are considered key stakeholders and hold positions on the study's stakeholder council, which also includes experts on homelessness, physicians, social workers focused on homelessness, and other community partners. In recognition of their contributions and work on the project, veteran consultants are paid US\$25 per hour using cash vouchers redeemable at the Veterans Affairs hospital of their choice (Bedford or Boston). The vouchers can be redeemed in-person or via business-reply mail to facilitate payments for veterans who are unable to travel to the hospital site. As the study progresses, they will meet with research study team members as needed and participate in quarterly meetings of the stakeholder council to receive updates, voice concerns, and give feedback.

Case study D: improving access to alcohol misuse services

Drinking alcohol in excess can have a negative impact on physical and mental health [28,29]. The British Army has expressed concern that harmful drinking can undermine operational effectiveness and that established drinking patterns may be difficult to change upon leaving the Armed Forces. The aim of this project was to explore why veterans are reluctant to access help for alcohol problems and the extent to which they may be different from other

substance misuse service users within the general population. The study design employed an applied social policy research methodology, including in-depth semi-structured interviews with 19 UK veterans. Specific study details are described elsewhere [30,31]. The study took place in 2017 and arose from two frequently asked questions from clinicians working in alcohol misuse services. The questions related to difficulty in engaging veterans in treatment programs and, once they did engage, understanding why it is difficult to maintain engagement. Veterans were primarily involved in study design and peer recruitment for this study.

Initially, issues arose at the participant recruitment stage of this project. This study set out to explore, through semi-structured interviews, veterans' relationship with alcohol and why there appeared to be a reluctance to access help. Initial recruitment of participants took place with support from the NHS Trust involved in the study. However, it became apparent that participants who were accessing treatment and who consented to take part in the study were early in their recovery journey and reluctant to be interviewed face-to-face. This phase was, therefore, reviewed, and the research team enlisted the help of a third sector charity that focuses on homelessness and substance misuse. This service provider employed veterans as case workers and was able to evidence successful engagement with the veteran community to provide support with alcohol misuse issues. With support from the charity, the research team designed a peer recruitment model for participant recruitment. The peer recruiters, who had served in the UK Armed Forces and were employed by the charity, were able to recruit participants who were further on in their treatment journey and who were able to reflect on their experiences face-to-face with researchers.

Using this peer-recruitment model enabled social connections to arise from within the veteran community. This helped participants engage in the study. In addition, as a direct result of using a peer-recruitment approach, a veteran was appointed to the post of peer-support worker in the research team. This full-time, paid post was fundamental to securing continuation funding (based on recommendations from the research findings). It supported the implementation of a new model of care offering support for veterans accessing mental health and substance misuse services. The peer-support worker was at the centre of this new model of care.

Benefits, challenges & guidance for veteran involvement

The case studies depicted earlier bring to the forefront both benefits and challenges of involving veterans in each component of research. Some of these have been highlighted in the literature [32,33]. We discuss these in more detail in the following sections, organized by the phases of research described previously and bringing our experiences to guide future researchers in working with veteran partners as they move forward. Drawing from our experience working with veterans on our research teams, we also share recommendations for overcoming challenges at each point on the research cycle (See [Table 2](#)).

Stakeholder/steering group participation

Ongoing veteran participation in a stakeholder or steering group [34] can especially add value in situations where the study covers a particularly sensitive topic, as was the case in Case Study A, where veteran steering group members advised in all areas regarding veterans who have experienced limb loss, including addressing potential ethical concerns. Because one negative experience could have cancelled out many positive feelings that contributed to a willingness to participate in the study, it was important that all aspects of the study be reviewed for sensitivity and ethical compliance. In Case Study C, veterans were treated as stakeholders on a par with medical doctors, experts on homelessness, and others on the team. This level of inclusion created a familiarity with the project that augmented the veterans' own experiences and led to an authentic contribution to the research, which was recognized by funders and helped to get the study grant awarded.

To fully receive the value of involving veterans in a stakeholder group, researchers should enable veterans to participate completely [35]. Lack of communication can be a barrier to full participation that should be addressed over the course of the study. Veteran stakeholders should understand expectations for attendance and participation at the outset, and group meetings should be organized in a way that allows co-leadership and bidirectional communication. Ideally, researchers and veterans should co-create these expectations and meeting formats. It can also be helpful to select veterans who are already active in the community and thus share vocabulary surrounding the research topic.

Logistical challenges of including veterans in a stakeholder or steering group include geographical distance and demands on time of meeting regularly. We have found that flexibility and creativity can overcome these and related barriers: consider virtual meeting platforms, meeting outside of normal work hours, offering options to contribute offline, etc.

Set research agenda

An existing collaborative relationship with veterans and other stakeholders can also lead to future research – as seen in Case Study B, where the idea for the research came from the Veteran community. This type of community-academic partnership not only strengthens research [36,37] but can also lead to circumstances where, ideally, the research process doesn't end but continues iteratively with future studies [38].

Case Study B illustrates that strong relationships are central to the level of collaboration involved in successfully working with stakeholders to prioritise future research. While relationship-building occurs naturally over the course of working together as a study team, researchers may lose touch with veteran colleagues after the study has ended – leading to missed opportunities for veteran community needs to arise in conversation. By maintaining frequent contact with veterans and community organizations and building a relationship of collaboration, researchers can allow those opportunities to arise informally.

At other times, community members are involved more formally in setting a research agenda, as members of a stakeholder group or steering committee, which ensures regular contact with veterans and other community stakeholders. However, a potential barrier is perceived or actual power imbalances among members of the stakeholder group [39]. Practical techniques for overcoming this barrier include participating in learning and other activities together, as well as creating 'flat hierarchies' in the stakeholder group [40] – i.e., welcoming stakeholders as partners [41].

Study design consultation

The use of cell phones among the homeless population as described in Case Study C shows how involving veterans early in the process of developing a study can be useful in determining the feasibility of a project or aspects of a project. Veterans can draw upon their experience to identify solutions to overcome barriers when the topic is sensitive, for example in the design of materials such as interview guides (Case Studies B and C). Feedback from veteran stakeholders can also be incorporated in response to reviewer comments (Case Study C), and clearly demonstrated support from a peer research organization can make the case for funding (Case Study B).

It can be challenging to identify and involve veterans early in study development, especially prior to a grant being funded. However, study design consultation has more value when all stakeholders are involved at an earlier stage – providing input when it can be acted upon rather than feedback when it may be too late to make modifications [42]. We have identified in our work several facilitators to getting veterans involved early with study design consultation: conduct outreach, build awareness, and develop networks with related veteran organizations (and other resources where consultants might be found) wherever possible; screen candidates and create a database of available veterans in preparation for future research needs; and start as early as possible to enlist veteran stakeholders and address regulatory barriers, concomitant to identifying other members of the research team.

Another challenge to successful study design consultation is integrating veterans fully into the research team, which can be difficult in part due to the novelty of involving laypersons in research. A certain level of humility is required on the part of the investigator, and a genuine acknowledgement of veteran expertise by experience, for advice first to be freely shared and then to be incorporated in the research. To address challenges related to the veteran being accepted on the research team, we recommend investigator training and mentorship that encourages a shift in perspective toward one that embraces veterans as experts by experience. Veterans, for their part, may enter the consultation process with overly high expectations, especially regarding turnaround time from grant submission to funding to execution. They will benefit from being made aware of the long timeline for grant review and funding; checking in frequently throughout this period will help to keep veterans feeling engaged and included on the team.

Peer recruitment & data collection

Veterans were involved in peer recruitment and/or data collection in some way for each of our case studies, reflecting the crucial role of involvement at this level in building trust for research participants. In Case Study A, peer recruiters were active charity members who understood the emotional risk participants would be undertaking to share their story in qualitative interviews. Similarly, in Case Study B, recruitment for this potentially vulnerable population was enhanced by the peer researcher's involvement in the War Widows' Association, which contributed to the participants' sense that the research was meaningful and worthwhile; the peer researcher was also trained to conduct interviews and (as will be discussed further) qualitative analysis. And in Case Study D, veteran support workers were utilised for recruiting where more traditional recruiting methods fell short. We believe that peer involvement at this level (as was seen in Case Studies A, B and D) can reduce bias and improve data quality by minimizing the potential power imbalance between researcher and study participant. While veterans did not directly participate

in recruitment and data collection in Case Study C, their oversight was critical to ensuring enrollment as well as responsiveness to questions related to homelessness, mental health, and substance use.

We have encountered few challenges to involving veterans in this way, provided – as we advise for study design consultation – researchers consistently network with veterans and related organizations to maintain a database of potential candidates. One additional challenge arises from the fact that recruitment and data collection are research activities: therefore, veterans involved in these activities must be formally included on US/UK regulatory documentation and take any required trainings. Ample time and resources should be allocated to supporting veterans who need to take trainings and to ensure they act in accordance with regulations, including in areas such as privacy, informed consent, and information security, as well as in recruiting and data collection techniques.

Analysis

The peer researcher who conducted interviews for Case Study B also became involved in qualitative data analysis of the interviews. The peer researcher joined the analysis team after data were coded and initial themes generated, reviewing the themes and contributing to further abstraction of the data. Veterans can also contribute to data analysis as part of their role on a stakeholder group, as will be the case as Case Study C progresses. Veteran participation at this level can add authenticity to the findings; as veteran peers on the team confirm inferences and highlight themes that resonate with them, the analysis moves in a direction that is more likely to be valued by the study's targeted population. Veterans can also draw from their experiences to call attention to ways that findings can be readily translated into program activities that positively impact veteran communities [43,44].

The most consequential challenge to veteran involvement in data analysis is simply the lack of awareness on the part of most researchers that this level of involvement is a possibility. In our experience to date, data analysis has naturally evolved as an extension of recruitment and data collection activities; indeed, working with a veteran who is already a familiar and trusted member of the research team can help overcome research team hesitancy. Researchers can also invite peer contributions to data analysis by asking veterans to compare overall themes and analytical inferences with their own experience, to confirm validity.

Dissemination

Veteran peer researchers can support study report writing and attend formal meetings and conferences (academic or in the lay community) to help present study findings (Case Study B). Inviting peers and other stakeholders to present in forums outside of academia, to audiences directly impacted by the findings, can help spread research benefits beyond the research community [45,46]. Dissemination can also be more impactful when stakeholders are directly asked when, how, and with whom the research should be shared, as they were in Case Study B. Regardless of the forum, it can be very powerful when veterans themselves present the information that is about them.

Depending on the situation, in our experience cost (in terms of both money and time) can prohibit some stakeholders from attending dissemination events. Some veterans may be uncomfortable speaking in public or may prefer to present to their peers rather than at an academic conference. We recommend being selective about the appropriate forum for individual speakers, and then being both flexible and supportive in helping veterans prepare for the event. Veterans may want to speak for only part of the presentation, for example, or to co-present with a member of the research team; or being made aware that their authentic voice will be a welcome and refreshing addition to an academic presentation may be all that is needed to build their enthusiasm. Finally, having a backup speaker or co-speaker available can relieve anxiety and ensure that someone from the team is able to give or help give the presentation when the time comes.

Translation into practice

In Case Study D, a veteran was hired to implement recommendations that developed from the study, thus completing the research cycle [47]. This study represents a potential benefit of involving veterans in research: the opportunity for the peer researcher to serve as a model for the intervention. While identifying continued funding for translating any intervention into practice after a study is complete is often an issue [48], it is possible – as was our experience in Case Study D – that the presence of the peer researcher will facilitate the funding and hiring processes. In addition to the knowledge and experience they gained in the study, the peer researcher had developed social connections that enabled the intervention to continue smoothly. To ensure success in continuing with the program after the study is completed, one caveat is to identify a peer recruiter who has the appropriate kind and

level of shared military experience. As there are many pathways to military experience, veteran status may not be sufficient for ongoing success with the intervention.

Discussion

Drawing on our experiences working with veterans on studies, this paper illustrates how involving veteran experts by experience in the research process – although not without challenges – can have benefits throughout the research cycle. While this population may be considered by some as difficult to engage in research, numerous mechanisms exist for overcoming this challenge. The mechanics of building trust in research can be most readily observed in peer recruitment and data collection, where veteran peers engage directly with potential study participants, operating as ‘insiders’ [49] in a way that academic researchers cannot. Engagement of veterans and their family members on the research team at all phases of the research cycle can build trust by aligning research with participants’ own experiences as veterans. When veterans contribute to other, less visible parts of the research cycle, these contributions may not be immediately recognized by their peers but are reflected in improvements in study design feasibility, realistic recruitment methods, respectful interview guides and survey instruments, and dissemination of study findings to a lay audience that includes the participants themselves.

We found that engaging veterans in the research process also allows veterans to observe the thoughtful and methodical way that research is conducted, from forming an initial research question, through grant submission, and ultimately to dissemination and translation of research findings. Veterans become familiar with the regulatory oversight that ensures ethical research practices and protects participants from research misconduct. Working directly with academicians, these veteran peers become representatives of a larger community of researchers, thus continuing to build trust after the study is completed.

Conclusion

We have described four studies that address sensitive topics related to military and veteran experience. In each of these cases, we engaged veterans in the research at various phases of the research cycle. Realizing the benefits and overcoming the barriers to veteran engagement in research led to the development of best practices, which is here presented as guidance for researchers wishing to engage veterans, family members and other related stakeholders in their research.

Summary points

- Military veterans form a unique population that face many challenges to participating in research, including lack of trust. Engaging veterans in the research process, which builds on the sense of comradery that is part of military culture, can help to overcome veterans’ lack of trust in research.
- Our research teams have successfully engaged veterans in research studies in the UK and the USA.
- This article describes studies about veterans who have experienced limb loss; casualty notification of war widows; technology use by veterans with histories of homelessness and substance abuse; and improving access to alcohol misuse services.
- The studies highlight the benefits and challenges of involving veterans in every component of research and lessons on how to overcome the challenges.
- Veterans can be engaged throughout the research cycle – study design consultation, stakeholder/steering group participation, peer recruitment and data collection, analysis and dissemination.
- Specific guidance for how best to involve veterans depends on exactly how they’re being engaged.
- Continuing to involve veterans after the research study has ended can lead to future research and further strengthen community-academic partnerships.
- The veterans who are involved in research studies have a unique opportunity to observe research in action, and they become representatives of the larger research community. This continues the process of building veterans’ trust in research.

Author contributions

A Barker, S Dunlap, CW Hartmann, G Wilson-Menzfeld, G McGill contributed to conception and design of the paper; S Dunlap, G Wilson-Menzfeld contributed case studies; all contributed to interpretation of case studies; A Barker, CW Hartmann responsible for initial draft and all authors contributed to drafting and refinement of paper, including important intellectual content contributions.

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Ethical conduct of research

The authors state that studies reviewed in this article obtained appropriate institutional review board approval and when applicable informed consent from human subjects. This paper reports no study data.

References

Papers of special note have been highlighted as: ● of interest; ●● of considerable interest

- Olenick M, Flowers M, Díaz VJ. US veterans and their unique issues: enhancing health care professional awareness. *Adv. Med. Educ. Pract.* 6, 635–639 (2015).
- **Overview of mental health, physical health, and social issues faced by military veterans intended for health care professional awareness.**
- Bloeser K, Mccarron KK, Merker VL *et al.* “Because the country, it seems though, has turned their back on me”: Experiences of institutional betrayal among veterans living with Gulf War Illness. *Soc. Sci. Med.* 284, 114211 (2021).
- **Highlights the unique experiences of veterans and the importance of trust among veterans seeking healthcare.**
- Godier-McBard LR, Cable G, Wood AD, Fossey M. Gender differences in barriers to mental healthcare for UK military veterans: a preliminary investigation. *BMJ Mil. Health* 168(1), 70–75 (2022).
- Haro E, Mader M, Noel PH *et al.* The impact of trust, satisfaction, and perceived quality on preference for setting of future care among veterans with PTSD. *Mil. Med.* 184(11-12), e708–e714 (2019).
- Balbale SN, Locatelli SM, Lavela SL. Through their eyes: lessons learned using participatory methods in health care quality improvement projects. *Qual. Health Res.* 26(10), 1382–1392 (2016).
- Mullins CD, Tanveer S, Graham G, Baquet CR. Advancing community-engaged research: increasing trustworthiness within community-academic partnerships. *J. Comp. Eff. Res.* 9(11), 751–753 (2020).
- Littman AJ, True G, Ashmore E, Wellens T, Smith NL. How can we get Iraq- and Afghanistan-deployed US Veterans to participate in health-related research? Findings from a national focus group study. *BMC Med. Res. Methodol.* 18(1), 88 (2018).
- Flynn L, Krause-Parello C, Chase S *et al.* Toward veteran-centered research: a veteran-focused community engagement project. *Journal of Veterans Studies* 4(2), 265–277 (2019).
- Johnston LG, Hakim AJ, Dittrich S, Burnett J, Kim E, White RG. A systematic review of published respondent-driven sampling surveys collecting behavioral and biologic data. *AIDS Behav.* 20(8), 1754–1776 (2016).
- Langer SL, Castro FG, Chen AC *et al.* Recruitment and retention of underrepresented and vulnerable populations to research. *Public Health Nurs.* 38(6), 1102–1115 (2021).
- Braun LA, Kennedy HP, Sadler LS, Dixon J. Research on U.S. military women: recruitment and retention challenges and strategies. *Mil. Med.* 180(12), 1247–1255 (2015).
- Merker VL, Hyde JK, Herbst A *et al.* Evaluating the impacts of patient engagement on health services research teams: lessons from the veteran consulting network. *J. Gen. Intern. Med.* 37(Suppl. 1), 33–41 (2022).
- **Presents a logic model for assessing the impact of patient engagement programs. Qualitative interviews present outcomes from perspectives of both researchers and veteran consultants.**
- Monteith LL, Wendleton L, Bahraini NH, Matarazzo BB, Brimmer G, Mohatt NV. Together with veterans: VA national strategy alignment and lessons learned from community-based suicide prevention for rural veterans. *Suicide Life Threat. Behav.* 50(3), 588–600 (2020).
- Yan A, Hooyer K, Asan O, Flower M, Whittle J. Engaging veteran stakeholders to identify patient-centred research priorities for optimizing implementation of lung cancer screening. *Health Expectations* 25(1), 408–418 (2022).
- Knight SJ, Haibach JP, Hamilton AB *et al.* Veteran engagement in health services research: a conceptual model. *J. Gen. Intern. Med.* 37(Suppl. 1), 94–98 (2022).

- **A Veterans Affairs working group has developed a conceptual model that identifies potential veteran stakeholder roles and makes recommendations for future veteran engagement in research.**
- 16. Dillon EC, Tuzzio L, Madrid S, Olden H, Greenlee RT. Measuring the impact of patient-engaged research: how a methods workshop identified critical outcomes of research engagement. *J. Patient Cent. Res. Rev.* 4(4), 237–246 (2017).
- 17. NIHR Research Design Service. *Patient and public involvement in health and social care research: a handbook for researchers*. Research Design Service, London, UK (2018).
- 18. Edwards HA, Huang J, Jansky L, Mullins CD. What works when: mapping patient and stakeholder engagement methods along the ten-step continuum framework. *J. Comp. Eff. Res.* 10(12), 999–1017 (2021).
- 19. Caddick N, McGill G, Greaves J, Kiernan MD. Resisting decline? Narratives of independence among aging limbless veterans. *Journal of Aging Studies* 46, 24–31 (2018).
- 20. McGill G, Wilson G, Caddick N, Forster N, Kiernan MD. Rehabilitation and transition in military veterans after limb-loss. *Disability and Rehabilitation* 43(23), 1–8 (2021).
- 21. Wilson G, McGill G, Osborne A, Kiernan MD. Housing needs of ageing veterans who have experienced limb loss. *Int J Environ Res Public Health.* 17(5), 1791 (2020).
- 22. McGill G, Wilson G, Caddick N, Kiernan MD. Peer-led recruitment of ‘hard to reach’ older limbless veterans: A case-study discussion. *3rd World conference on Qualitative Research*. Lisbon, Portugal (2018).
- 23. McGill G, Wilson G. War widows ‘Knock on the Door’ phase one report (2020). <https://covenantfund.org.uk>
- 24. North CS, Wohlford SE, Dean DJ *et al.* A pilot study using mixed GPS/narrative interview methods to understand geospatial behavior in homeless populations. *Community Ment. Health J.* 53(6), 661–671 (2017).
- 25. Muehlenkamp JJ, Engel SG, Wadeson A *et al.* Emotional states preceding and following acts of non-suicidal self-injury in bulimia nervosa patients. *Behaviour Research and Therapy* 47(1), 83–87 (2009).
- 26. McInnes DK, Li AE, Hogan TP. Opportunities for engaging low-income, vulnerable populations in health care: a systematic review of homeless persons’ access to and use of information technologies. *Am. J. Public Health* 103(S2), e11–e24 (2013).
- **Homeless veterans do have regular access to mobile phones. Knowing this, investigators can choose to work with veterans experiencing homelessness as consultants, with fewer concerns about maintaining contact.**
- 27. McInnes DK, Sawh L, Petrakis BA *et al.* The potential for health-related uses of mobile phones and internet with homeless veterans: results from a multisite survey. *Telemedicine and e-Health* 20(9), 801–809 (2014).
- 28. Rona RJ, Jones M, Fear NT, Hull L, Hotopf M, Wessely S. Alcohol misuse and functional impairment in the UK armed forces: a population-based study. *Drug Alcohol. Depend.* 108(1-2), 37–42 (2010).
- 29. Aguirre M, Greenberg N, Sharpley J, Simpson R, Wall C. Alcohol consumption in the UK armed forces: are we drinking too much? *JR Army Med. Corps.* 160(1), 72–73 (2014).
- 30. Kiernan MD, Osbourne A, McGill G, *et al.*, Are veterans different? Understanding veterans’ help-seeking behaviour for alcohol problems. *Health Soc Care Community.* 26 (5), 725–733 (2018).
- 31. The Northern Hub for Veterans and Military Families Research. Improving access report 2017: understanding why veterans are reluctant to access help for alcohol problems (2017). www.vfrhub.com/article/improving-access-report-2017-understanding-why-veterans-are-reluctant-to-access-help-for-alcohol-problems/
- 32. Bird M, Ouellette C, Whitmore C *et al.* Preparing for patient partnership: a scoping review of patient partner engagement and evaluation in research. *Health Expect.* 23(3), 523–539 (2020).
- **A review that identifies barriers and facilitators to patient research partnerships, as well as potential impact/outcomes. Highlights the need for addressing power dynamics on research teams.**
- 33. Kirwan JR, De Wit M, Frank L *et al.* Emerging guidelines for patient engagement in research. *Value Health* 20(3), 481–486 (2017).
- 34. Anicich A, Katsoch L, Kerns RD. Engaging veterans and military service members to optimize pragmatic clinical trials of nonpharmacological approaches for pain management. *Pain Med.* doi:10.1093/pm/pnac020 (2022).
- 35. Supple D, Roberts A, Hudson V *et al.* From tokenism to meaningful engagement: best practices in patient involvement in an EU project. *Res. Involv. Engagem.* 1, 5 (2015).
- 36. Brush BL, Mentz G, Jensen M *et al.* Success in long-standing community-based participatory research (CBPR) partnerships: a scoping literature review. *Health Educ. Behav.* 47(4), 556–568 (2020).
- 37. Tigges BB, Miller D, Dudding KM *et al.* Measuring quality and outcomes of research collaborations: an integrative review. *J. Clin. Transl. Sci.* 3(5), 261–289 (2019).
- 38. Kilbourne AM, Goodrich DE, Miale-Lye I, Braganza MZ, Bowersox NW. Quality enhancement research initiative implementation roadmap: toward sustainability of evidence-based practices in a learning health system. *Medical Care* 57(10 Suppl. 3), S286–S293 (2019).
- 39. Abma TA. Dialogue and deliberation: new approaches to including patients in setting health and healthcare research agendas. *Action Research* 17(4), 429–450 (2019).

40. Kaisler RE, Missbach B. Co-creating a patient and public involvement and engagement ‘how to’ guide for researchers. *Res. Involv. Engagem.* 6, 32 (2020).
41. Pozniak K, Buchanan F, Cross A *et al.* Building a culture of engagement at a research centre for childhood disability. *Res. Involv. Engagem.* 7(1), 78 (2021).
42. Sheridan S, Schrandt S, Forsythe L, Hilliard TS, Paez KA, Advisory Panel on Patient E. The PCORI Engagement Rubric: Promising Practices for Partnering in Research. *Annals of Family Medicine* 15(2), 165–170 (2017).
43. Locock L, Kirkpatrick S, Brading L *et al.* Involving service users in the qualitative analysis of patient narratives to support healthcare quality improvement. *Res. Involv. Engagem.* 5, 1 (2019).
44. Locock L, Kirkpatrick S, Brading L *et al.* Response to “comments on”: involving service users in the qualitative analysis of patient narratives to support healthcare quality improvement. *Res. Involv. Engagem.* 5, 26 (2019).
45. Elwy AR, Maguire EM, Kim B, West GS. Involving stakeholders as communication partners in research dissemination efforts. *J. Gen. Intern. Med.* 37(Suppl. 1), 123–127 (2022).
46. Poger JM, Murray AE, Schoettler EA, Marin ES, Aumiller BB, Kraschnewski JL. Enhancing community engagement in patient-centered outcomes research: equipping learners to thrive in translational efforts. *J. Clin. Transl. Sci.* 5(1), e172 (2021).
47. Schmittziel JA, Grumbach K, Selby JV. System-based participatory research in health care: an approach for sustainable translational research and quality improvement. *Ann. Fam. Med.* 8(3), 256–259 (2010).
48. Brownson RC, Fielding JE, Green LW. Building capacity for evidence-based public health: reconciling the pulls of practice and the push of research. *Annu. Rev. Public Health* 39, 27–53 (2018).
49. Ryan L, Kofman E, Aaron P. Insiders and outsiders: working with peer researchers in researching Muslim communities. *Int. J. Social Res. Methodol.* 14(1), 49–60 (2011).