PROJECT | RESPECT

Empowerment through Research for People Experiencing Homelessness

Considerations for Engaging People with Lived Experience as Stakeholders in Patient-Centered Comparative Effectiveness Research

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Background

Over 653,000 people experienced homelessness (PEH) in the United States (U.S.) in 2023, an increase of 12 percent from 2020 levels.[1] These individuals are among the nation's most socially marginalized and medically vulnerable. The material hardships, exposure to violence, and psychological traumas of being unhoused dramatically increase PEH's risk for disease, mental illness, and substance misuse.[2] Yet once they develop these conditions, PEH are less likely than most individuals to get treatment, and on the rare occasions that they do, the services they receive are insufficient and/or of poor quality.[3] Consequently, PEH die approximately 20 years earlier than their housed counterparts.[4]

The crisis of homelessness and health has spurred action, leading to the investment of hundreds of millions from the National Institutes of Health (NIH), the Department of Veterans Affairs (DVA), the Patient-Centered Outcomes Research Institute (PCORI), and other funders to invest substantially in research on how to improve healthcare and health outcomes for PEH.[5] Over the past several years, researchers have begun engaging individuals who have lived experience with homelessness as partners for this work.[6] Lived experience is critical for homelessness research since insights from individuals who are affected by complex social, economic, and public health issues (such as homelessness) have unique insights that can be used to ensure that studies (a) ask questions related to outcomes that matter to the patient population, and (b) produce answers that are relevant for the real-world challenges patients face.[7] This is particularly important for research related to homelessness and health because even the interventions with the strongest evidence-base—such as Permanent Supportive Housing that provides comprehensive services using a Housing First approach—have not yet been demonstrated to yield significant

[1] de Sousa T, Andrichik A, Presterea E, Rush K, Tano C, Wheeler M. *2023 Annual Homeless Assessment Report: Part 1 - PIT Estimates of Homelessness in the U.S. | HUD USER*. U.S. Department of Housing and Urban Development.; 2023. Accessed December 21, 2023. https://www.huduser.gov/portal/datasets/ahar/2023-ahar-part-1-pit-estimates-of-homelessness-in-the-us.html

[2] Richards J, Kuhn R. Unsheltered Homelessness and Health: A Literature Review. *AJPM Focus*. 2023;2(1):100043. doi:10.1016/j.focus.2022.100043

[3] Buccieri, K. (2020). Homeless patients associate clinician bias with suboptimal care for mental illness, addictions, and chronic pain. *Journal of Primary Care and Community Health*, *11*, 1–7. https:// doi.org/10.1177/2150132720910289; Jones, A. L., Haussman, L. R., Haas, G. L., Mor, M. K., Cashy, J. P., Schaefer, J. H., & Gordon, A. J. (2017). A national evaluation of homeless and nonhomeless veterans' experiences with primary care. *Psychological Services*, *14*(2), 174–183S

[4] Meyer BD, Wyse A, Bosma H. *Life and Death at the Margins of Society: The Mortality of the U.S. Homeless Population*. Becker Friedman Institute for Economics at the University of Chicago; 2015. Accessed January 11, 2024. https://bfi.uchicago.edu/insight/research-summary/the-mortality-of-the-us-homeless-population/

[5] Padwa, H., Henwood, B. F., Ijadi-Maghsoodi, R., Tran-Smith, B., Darby, A., Bluthenthal, R., ... & Gelberg, L. (2023). Bringing Lived Experience to Research on Health and Homelessness: Perspectives of Researchers and Lived Experience Partners. *Community Mental Health Journal*, 1-8.

[6] Ibid.; Fletcher, E. H., Gabriellan, S., Brown, L., Gough, J. C., Ijadi-Maghsoodi, R., Kolofonos, I., Nazinyan, M., Orellana, E., & Wells, K. (2022). Lessons learned by collaborating with structurally vulnerable veterans via a Veterans Engagement Group. Journal of General Internal Medicine, 37(S1), 109–112. https://doi.org/10.1007/ s11606-021-07075-y; Franco, A., Meldrum, J., & Ngairuiya, C. (2021). Identifying homeless population needs in the emergency department using communitybased participatory research. BMC Health Research, 21(428), https://doi.org/10.1186/s12913-021-06426-z; Kiser, T., Hulton, L. (2018). Addressing health care needs in the homeless population: A new approach using participatory action research. SAGE Open, 8(3), https://doi.org/10.1177/215824401878975

[7] Guerrero Ramirez, G., Bradley, K., Amos, L., Jean-Baptiste, D., Ruggiero, R., Marki, Y…Benton, A. (2023). *What Is Lived Experience?* U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation. Retrieved from https://aspe.hhs.gov/lived-experience February 22, 2024

improvements in most health-related outcomes.[8] More research on how to produce positive health-related outcomes for PEH is needed, and bringing the voices of PEH to this work may be one of the keys to finding answers that have remained elusive. Involving PEH in every step of the research process—from formulating questions to interpreting results—can help generate real-world answers to real-world problems.

To support these developments, PCORI contracted with us—a group of Los Angeles-based researchers and PEH—to develop *Resources to Empower Persons Experiencing homelessness in Comparative Trials (Project RESPECT).* Our collaboration began in 2020 when we came together to design and implement the *Person Centered Housing Options, Outcomes, Services, & Environment (PCHOOSE)* study, a PCORI-funded project examining the comparative effectiveness of different permanent supportive housing configurations in producing patient-centered health and COVID-19 outcomes for PEH.[9] Building on our successful collaboration in PCHOOSE, we engaged in *Project RESPECT* to develop resources that could help PCORI and other research/PEH collaboratives across the country improve patient-centered research related to homelessness.

This guide shares lessons learned about engaging PEH in research partnerships by the *Project RESPECT* group from the time it started working together in 2020 through early 2024. In both *PCHOOSE* and *Project RESPECT,* our group had many collaborative successes, both proposing and implementing innovative projects that we believe will generate knowledge that can meaningfully advance the field of research on homelessness and health.[10] We also have had some

[8] National Academies of Sciences, Engineering, and Medicine. (2018). Permanent supportive housing: Evaluating the evidence for improving health outcomes among people experiencing chronic homelessness. Woodhall-Melnik, J. R., & Dunn, J. R. (2016). A systematic review of outcomes associated with participation in Housing First programs. *Housing Studies*, *31*(3), 287-304; Baxter, A. J., Tweed, E. J., Katikireddi, S. V., & Thomson, H. (2019). Effects of Housing First approaches on health and well-being of adults who are homeless or at risk of homelessness: systematic review and meta-analysis of randomised controlled trials. *J Epidemiol Community Health*, *73*(5), 379-387; Peng, Y., Hahn, R. A., Finnie, R. K., Cobb, J., Williams, S. P., Fielding, J. E., ... & Community Preventive Services Task Force. (2020). Permanent supportive housing with housing first to reduce homelessness and promote health among homeless populations with disability: a community guide systematic review. *Journal of Public Health Management and Practice*, *26*(5), 404-411.

[9] *Comparative Effectiveness of Single-Site and Scattered-Site Permanent Supportive Housing on Patient-Centered and COVID-19 Related Outcomes for People Experiencing Homelessness.* (2020). Retrieved from https://www.pcori.org/research-results/2020/comparative-effectiveness-single-site-and-scattered-site-permanent-supportive-housing-patient-centered-and-covid-19-related-outcomes-people-experiencing-homelessness February 22, 2024.

[10] Darby, A., Padwa, H., Stevens, R., King, D. Nothing About Us Without Us: Perspectives of Individuals with Lived Experience on Homelessness Research. American Public Health Association Annual Meeting, Online, 2021; Henwood, B. F., Kuhn, R., Padwa, H., Ijadi-Maghsoodi, R., Corletto, G., Lawton, A., ... & Gelberg, L. (2023). Investigating the Comparative Effectiveness of Place-Based and Scatter-Site Permanent Supportive Housing for People Experiencing Homelessness During the COVID-19 Pandemic: Protocols for a Mixed Methods, Prospective Longitudinal Study. *JMIR research protocols*, *12*(1), e46782.; Henwood, B., Kuhn, R., Gonzalez, A.L., Chien, J., Tu, Y, Bluthenthal, R., Cousineau, M., Padwa, H., et al., (in press) Characteristics of individuals approved for permanent supportive housing in Los Angeles County, CA, during the COVID-19 pandemic: Baseline results from the PCHOOSE study. *Administration and Policy in Mental Health.* Lawton, A., Kuhn, R., Henwood, B., Chien, J., Gelberg, L., Padwa, H., Cousineau, M. Drivers of COVID-19 Vaccine Uptake Among People Experiencing Homelessness Transitioning Into Permanent Supportive Housing in Los Angeles, CA. Oral Presentation. American Public Health Association Annual Meeting, Boston MA, 2022; Padwa et al., 2023; Padwa, H., Ijadi-Maghsoodi, R., Tran-Smith, B., Darby, A., Harris, Y., Patanwala, M., Henwood, B., Fenderson, E., Galarza, E., Haynes, A., King, D., Marshall, P., Martiniuk, E., Patton, T., Shaw, S., Stevens, R., Gelberg, L. Where Should We Go? Benefits and Drawbacks of Place-Based and Scattered-Site Permanent Supportive Housing for People Experiencing Homelessness – Initial Qualitative Findings of the Person-Centered Housing Options, Outcomes, Services, & Environment (PCHOOSE) Study. Patient-Centered Outcomes Research Institute Annual Meeting, Online, 2022; Smith, B. T., Padwa, H., Ijadi-Maghsoodi, R., Darby, A., Harris, T., Patanwala, M., ... & Gelberg, L. (2022, November). How Do We Keep Everyone Safe?: Client and Provider Perspectives on the Implementation and Impact of

missteps in our work together and learned many lessons about what *not* to do in researcher-PEH partnerships. In this document, we bring together insights on what we have done well and things we should have done differently in our collaboration to create a roadmap that other stakeholders can use to replicate (or exceed) our successes, while avoiding some of the pitfalls that obstructed us along the way.

We do not provide step-by-step guidance on research stakeholder engagement, since other resources on this topic exist,[11] and many specifics of stakeholder engagement for PEH will vary project-by-project. Instead, we lay out key considerations that groups need to consider when working with PEH as research stakeholder partners. These include:

1) Specific needs and strengths of PEH
2) PEH characteristics and experiences' impacts on stakeholder group activities
3) Being productive while meeting stakeholder needs

COVID-19 Safety Protocols in Los Angeles County Homeless Shelters. In *2022 APPAM Fall Research Conference*. APPAM; Smith, B.T., Padwa, H., Ijadi-Maghsoodi, R., Patanwala, M., Harris, T., Gelberg, L., Henwood, B. Beyond Housing: An Exploration of Neighborhood Socio-Spatial Context on Permanent Supportive Housing Tenants' Overall Wellbeing. Society for Social Work and Research, Annual Conference, Washington DC, 2024; Smith, B.T., Padwa, H., Shaw, S., Ijadi-Maghsoodi, R., La Motte-Kerr, W., Darby, A., Gelberg, L., Henwood, B.F. Nothing About Us Without Us: Stakeholder Engagement in Homelessness Research. Association for Public Policy Analysis & Management Annual Meeting, Austin TX, 2022.

[11] Patient-Centered Outcomes Research Institute (2021). *Building Effective Multi-Stakeholder Research Teams.* Retrieved from https://research-teams.pcori.org/?utm_campaign=Building+Effective+Multi-Stakeholder+Research+Teams&utm_medium=bitly&utm_source=website; Zimmerman, E., Cook, S. (2017). *The SEED Method Toolkit: Overview and Summary.* Retrieved from https://societyhealth.vcu.edu/media/society-health/pdf/SEEDMethodToolkitBrochure.pdf;; Padwa, H., Antonini, V., Grossman, J., Ling, W. (2017). *Stakeholder Engagement Methodology Report: Engaging Stakeholders in Patient-Centered Comparative Effectiveness Research on Substance Use Disorder Treatment.* Retrieved from https://www.pcori.org/research-results/2014/stakeholders-substance-use-research-and-treatment-information-exchange-ssurtie

Specific needs and strengths of PEH

Most PEH face significant traumas, and socio-political, economic, and health-related challenges due to the circumstances that preceded homelessness and/or things they experienced while unhoused. Surviving homelessness also requires them to develop significant strength and perseverance (see Figure 1). Many of these characteristics and experiences—particularly those related to poverty—endure even as PEH exit homelessness.

Figure 1: Specific Needs and Strengths of PEH
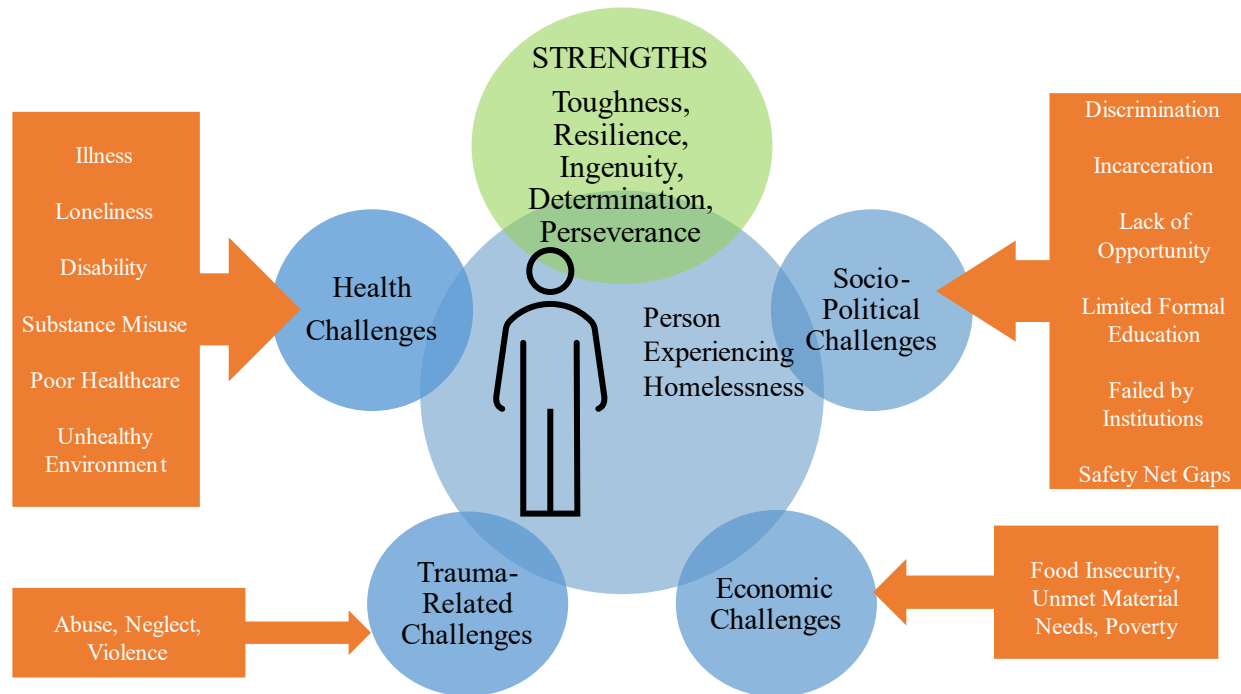
PEH needs and strengths' impacts on stakeholder group activities

All of these factors impact stakeholder group planning and activities in different ways, including:

- *Remote (not in-person) Communication:* Due to economic challenges, many PEH have limited access to communication technologies (e.g. cellular phones, computers) that are taken for granted in most research projects. Even when they own communications equipment, PEH may have inconsistent or limited data plans, and they may not have private or quiet places where they can talk. In addition, some PEH may have limited experience communicating via e-mail or text, increasing risks for miscommunication. Consequently, research teams need to be prepared to communicate with PEH in different ways during recruitment and engagement phases of projects, ask PEH directly about their communication needs and preferences, and tailor communication strategies for each lived experience stakeholder appropriately.

- *Compensation:* Lived experience is an invaluable asset for research on health and healthcare for PEH, and it is important to compensate PEH for their time and expertise. Yet many PEH have had experiences where they are asked for input or to provide insights free of charge or for little money, furthering their mistrust of institutions. Moreover, research funds that compensate PEH for their time can be a valuable source of extra income, particularly since many PEH struggle with economic challenges and poverty both during and after homelessness. Consequently, it is critical to communicate to PEH that their expertise is *highly valued* and that research teams want to compensate them fairly for their time. However, many PEH rely on public benefits for housing, income, and healthcare services, and providing them with too much compensation could impact their eligibility for these services or the amount of support they receive. Fairly paying PEH for their time and expertise while also being cognizant of the unintended consequences of providing financial compensation is a complicated issue that should be discussed with each PEH stakeholder individually prior to having them engage in stakeholder group activities. By doing this, research groups can design compensation plans that fit the needs and preferences of each PEH stakeholder and emphasize how much they value PEH's input into the research process.

- *Meeting Logistics:* Generally stakeholder groups meet in-person or via teleconference platforms such as Microsoft Teams and Zoom. Due to economic challenges, either or both options may inhibit PEH participation. For some PEH, lack of a car or limited access to safe and efficient public transportation could make attendance at in-person meetings difficult; in these cases, research teams should consider providing transportation for PEH to join meetings by arranging rides for them or arranging taxi or ride-share services, or they could turn in-person meetings into hybrid meetings that PEH participants can attend virtually. For PEH who lack access to the resources needed to join meetings by phone or online, research teams could consider providing stakeholders with phones, data plans, and computers they need to participate in virtual meetings. Alternatively, they could provide in-person options for attendance at online meetings by convening PEH stakeholders in one central location where they can join virtual meetings via teleconference.

- *Establishing, Implementing, and Maintaining Safe, Trauma-Informed Environments:* The traumas that most PEH face are dramatic and can have emotional, behavioral, physical, developmental, cognitive, interpersonal, and spiritual consequences that last lifetimes (see Figure 2). Consequently, it is critical to bring a trauma-informed approach to all group activities, building them on principles of safety, trustworthiness and transparency, collaboration and mutuality, empowerment, and attention to cultural, historical, and gender issues. Researchers from the Urban Institute and San Francisco State University have identified several strategies and practices that can help stakeholder groups operationalize the principles of trauma-informed care into group facilitation activities. These include using group organization and meetings as avenues to promote participant well-being, integrating peer-to-peer support into group meetings, creating spaces for

creative/personal expression and place-making (helping individuals heal and reframe narratives about themselves), and orienting discussions around principles of healing, emotional support, and restorative justice.[12] Trauma-informed practices include: acknowledging past harms and promoting consciousness of them; honoring history and celebrating culture; setting realistic expectations (since overpromising and then failing to come through reinforces mistrust); making community growth and accomplishments visible; ensuring consistency in communication and meeting structure; supporting clear and meaningful engagement; promoting safety; removing barriers to participation; fostering social cohesion; and creating space for group and individual reflection.[13] When communicating with PEH stakeholders, it is essential to communicate empathy (emotional connection, understanding perspectives and feelings of others) and compassion (genuine concern for the well-being of other members and a desire to alleviate their suffering) in order to build and maintain trusting relationships.

- *Ensuring Participant Comprehension of Group Activities and Discussion:* Due to life circumstances, many PEH do not have the same levels of formal education or expertise as other stakeholders, so concepts and questions that may seem simple to trained professionals may be difficult for PEH to understand quickly. Reviewing basic concepts and information about research, data, and the research process with PEH stakeholders, keeping language simple and jargon-free, and displaying data or statistics in visual formats and with laymen's terms can help ensure that all stakeholders comprehend information being reviewed and understand its meaning.

Figure 2: Impacts of Trauma[14]

Impact of Trauma on Individuals

Emotional	Behavioral	Physical	Developmental	Cognitive	Interpersonal	Spiritual
• Difficulty regulating emotions • Emotional numbness • Depression and anxiety • Post traumatic stress disorder	• Substance use • Self-destructive behaviors • Avoidance of situations, people, and places	• Physical symptoms resulting from emotional distress, including headaches, high blood presssure, and fatigue • Hyperarousal resulting in muscle tension and insomnia	• Impact varies by age group • Children and elderly at greatest risk • Changes occur in brain development	• Impaired short-term memory • Decreased focus or concentration • Feeling alienated or ashamed • Dissociation, depersonalization, and derealization • Flashbacks or re-experiences of the event	• Withdrawal from family, friends, community • Difficulty trusting others	• Depression and loneliness can lead to feelings of abandonment and loss of faith • Over time can experience increased appreciation of life or enhanced spiritual well-being

[12] Falkenburger E, Arena O, Wolin, J. (2018). *Trauma-Informed Community Builidng and Engagement.* Urban Institute. Retrieved from www.urban.org/sites/default/files/publication/98296/trauma-informed_community_building_and_engagement_0.pdf

[13] Ibid.

[14] Substance Abuse and Mental Health Services Administration: *Practical Guide for Implementing a Trauma-Informed Approach.* SAMHSA Publication No. PEP23-06-05-005. Rockville, MD: National Mental Health and Substance Use Policy Laboratory. Substance Abuse and Mental Health Services Administration, 2023.

- *The Value of Mentorship:* Peer mentorship can be a trauma-informed practice and an effective tool to ensure participant comprehension and active participation in group activities. PEH who are more accustomed to participating in groups with researchers and policymakers have likely overcome many of the barriers that could otherwise inhibit PEH stakeholder engagement and can provide PEH who are less experienced with or concerned about integrating into research stakeholder activities with both guidance and assurance. Through role modeling, educating them about terms and concepts that they may not have learned in the past and advising them on strategies on how to make their voices heard, peer mentors can help ensure that PEH can succeed in and contribute to group activities, regardless of their past training or experiences. At the outset of group activities, identifying potential PEH mentors and pairing them with other PEH who would benefit from their support can help optimize all PEH stakeholders' experiences and their contributions to group activities.
- *Recognizing and Leveraging PEH's Strengths:* While PEH may have different needs from other stakeholders and enter group activities with certain challenges, they also have significant strengths that can impact group activities and functionality. To endure homelessness, PEH need to be tough, determined, and highly resilient in the face of constant deprivation and danger. Moreover, the "street smarts" needed to survive homelessness include strategic thinking and ingenuity. These are significant assets in any intellectual undertaking, including research. Stakeholder groups should utilize these assets to advance their work.

Being productive while meeting stakeholder needs

While stakeholder group planning and facilitation must attend to the aforementioned issues, it also needs to focus on accomplishing tasks in a timely manner. If group activities are not planned well or facilitated efficiently, the space and flexibility needed for trauma-informed facilitation can impede the completion of group tasks. Some strategies to promote productivity while adhering to the principles and practices described above include:

- *Having a schedule:* Deadlines can help promote productivity and accountability, and planning ahead can help ensure that each meeting or activity advances stakeholder groups towards accomplishing goals in some fashion. Toolkits such as the *SEED Method* developed by researchers at Virginia Commonwealth University[15] can help stakeholder group leaders map out group activities ahead of time and create a schedule to accomplish project tasks. Establishing meeting agendas and

[15]Zimmerman, E., Cook, S. (2017). *The SEED Method Toolkit: Overview and Summary.* Retrieved from https://societyhealth.vcu.edu/media/society-health/pdf/SEEDMethodToolkitBrochure.pdf; Zimmerman, E. B., Rafie, C. L., Moser, D. E., Hargrove, A., Noe, T., & Mills, C. A. (2020). Participatory action planning to address the opioid crisis in a rural Virginia community using the SEED Method. *Journal of Participatory Research Methods*, *1*(1); Rafie, C. L., Zimmerman, E. B., Moser, D. E., Cook, S., & Zarghami, F. (2019). A lung cancer research agenda that reflects the diverse perspectives of community stakeholders: process and outcomes of the SEED method. *Research Involvement and Engagement*, *5*, 1-12; Zimmerman, E. B., Cook, S. K., Haley, A. D., Woolf, S. H., Price, S. K., & Team, T. E. R. (2017). A patient and provider research agenda on diabetes and hypertension management. *American Journal of Preventive Medicine*, *53*(1), 123-129.

communicating to group members the purpose of each meeting can help groups stay on task and accomplish the work that needs to be done.

- *Effective facilitation—the right conversations at the right time:* The most important job of research stakeholder group facilitators is to ensure that meeting tasks are accomplished. However, it can be difficult to do this in a trauma-informed manner that leaves adequate space for participants to share their experiences and heal together. Tension between efficient and person-focused facilitation can lead to frustration, with group members feeling that their voices have not been heard in a trauma-informed way (if there is not enough space to share and heal) or that meetings were inefficient (if they do not accomplish their goals). Demarcating spaces and times in group meetings that are devoted specifically to personal sharing and healing, and others that focus on accomplishing tasks, can help avoid these situations. At the beginning of meetings, grounding exercises and group sharing activities can be used to help PEH feel welcome, heard, and safe, and setting aside time at the end of meetings for stakeholders to share their feelings and emotions can help provide a sense of closure at each meeting's conclusion. Taking time to educate stakeholder group participants about different types of conversations that the group will be having at different points during meetings can help clarify which parts of meetings are focused on healing and which parts need to be focused on accomplishment of specific tasks (see Figure 3). More focused and directive facilitation during practical conversations, and more free-flowing facilitation during activities focused on sharing and healing (emotional conversations, social conversations) can create clarity for both facilitators and group members about what types of discussions to expect during different times.

Figure 3: Different Types of Conversations in Stakeholder Group Meetings, adapted from Duhigg (2024)[16]

Type of Conversation	Goal of Conversation	Nature of Conversation
Emotional	Discussion of feelings, building of empathy and connection	Free-flowing, loosely directed by facilitators
Social	Conversations about how we relate to each other, how we relate to society, how others relate to us	Free-flowing, loosely directed by facilitators
Practical	To identify problems and solutions, accomplish tasks	Action-oriented, directed by facilitators to achieve goals

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[16] Duhigg, C. (2024). *Supercommunicators: How to Unlock the Secret Language of Connection.* United States: Random House.

- *Having an individual with lived experience on the research team:* For researchers and group facilitators, it can be difficult to know how to balance the need for person-centered, trauma-informed stakeholder engagement with productivity. Having someone with lived experience on the research team—not as a stakeholder, but as a paid staff member—can help groups remain focused on getting work done while also being attentive to stakeholder needs. This individual (or individuals) can advise researchers and facilitators on strategies to lead groups efficiently while effectively implementing principles of trauma-informed facilitation. Conversely, they can advise lived experience stakeholders if they have difficulties with the group, serving as a bridge between research teams and group members who have lived experience. Furthermore, their inclusion in project leadership can ensure that the perspectives of lived experience are represented and included when making key decisions about the research group and its activities.

Conclusions and Next Steps

Through a collaboration of researchers, homeless service providers, and PEH, Project RESPECT identified key insights into the effective engagement of PEH in research partnerships. Our hope is that these insights help communities across the country bring together research and lived experience expertise in a way that enables them to generate solutions to the difficult question of how to improve the health and well-being of PEH.