



# What Does it Look Like to Equitably Engage People with Lived Experience?

Authors and contributors: Mathematica staff (Grace Guerrero Ramirez, Lauren Amos, Diana McCallum, Kate Bradley, Nkemdiriri Wheatley, Ryan Ruggiero, Tonyka McKinney, Scott Baumgartner); expert consultants with lived experience (Roger De Leon, Helena Girouard, Janine McMahon, and Wilnisha Sutton); and ASPE project officers (Laura Erickson, Amanda Benton).<sup>1,2</sup>

*This content was initially created to inform federal staff at the U.S. Department of Health and Human Services. In an effort to increase collaboration and share promising practices, the Office of the Assistant Secretary for Planning and Evaluation has made this tool available for both public and private partners. Potential audiences that may be interested in these materials include, but are not limited to, state and local governments, tribal governments, and other private or non-profit organizations focused on programs and policies relating to health and human services.*

## Purpose

It is important to engage people with lived experience in ways that value their insights and do not cause harm. People with lived experience are those directly affected by social, health, public health, or other issues and by the strategies that aim to address those issues. This gives them insights that can inform and improve research, policies, practices, and programs. This tool describes different components of ideal engagements with people with lived experience and contrasts them with components of inequitable engagements. This is not an exhaustive list, but you can use this tool to identify strengths and opportunities for making your team's engagements more equitable.<sup>3</sup>





## What is equity?

The consistent and systematic, fair, just, and impartial treatment of all individuals, including individuals who belong to underserved communities that have been denied such treatment, such as Black, Latino, and Indigenous and Native American persons, Asian Americans and Pacific Islanders and other persons of colors; members of religious minorities; lesbian, gay, bisexual, transgender, queer, and intersex (LGBTQI+) persons; persons with disabilities; persons who live in rural areas; and persons otherwise adversely affected by persistent poverty or inequality. *Definition adapted from [Executive Order 13985](#).*

<sup>1</sup> Suggested Citation: U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation. "What Does it Look Like to Equitably Engage People with Lived Experience?," by Grace Guerrero Ramirez, Lauren Amos, Diana McCallum, Kate Bradley, Nkemdiriri Wheatley, Ryan Ruggiero, Tonyka McKinney, Scott Baumgartner, Roger De Leon, Helena Girouard, Janine McMahon, Wilnisha Sutton, Laura Erickson, and Amanda Benton. Washington, District of Columbia: 2022.








<sup>2</sup> ASPE would like to thank and acknowledge the insights of numerous HHS staff who contributed to the content in this guide.

<sup>3</sup> For more information on how to equitably engage people with lived experience, see <https://aspe.hhs.gov/lived-experience>.

Engagement component	 <b>Equitable engagement</b>	 <b>Inequitable engagement</b>
 <b>Trust building</b>	<p><b>Acknowledges historical racism and other systemic barriers that may have contributed to communities' distrust of the government or service systems, and validates the experiences of those impacted or harmed by such systems</b></p> <p><b>Humanizes the engagement process and prioritizes meaningful engagement</b></p> <ul style="list-style-type: none"> <li>▪ Fosters relationship building, empathy and openness, and flexibility regarding the constraints people face</li> <li>▪ Builds in time and space for check-ins, activities, and discussions that encourage people with lived experience and federal staff to connect on a deeper level</li> <li>▪ Implements an intentional, well-planned engagement process</li> </ul> <p><b>Creates space for honest, safe dialogue</b></p> <ul style="list-style-type: none"> <li>▪ Involves credible and culturally competent facilitators who respect people's experiences and have the skills to make people feel safe in sharing their insights</li> <li>▪ Uses facilitation methods that allow everyone to provide input</li> </ul>	<p><b>Fails to acknowledge historical racism and other systemic barriers that may have contributed to communities' distrust of service systems, and minimizes or denies experiences of those impacted or harmed by systems</b></p> <p><b>Prioritizes meeting deadlines over building trust and gathering meaningful input</b></p> <ul style="list-style-type: none"> <li>▪ Imposes rigid processes and forms of communication</li> <li>▪ Focuses on transactional activities that aim to extract information from people</li> <li>▪ Implements a rushed engagement as an afterthought</li> </ul> <p><b>Inhibits participation</b></p> <ul style="list-style-type: none"> <li>▪ Involves facilitators who do not welcome people's experiences and insights, and do not appropriately intervene when harmful dynamics arise</li> <li>▪ Uses facilitation methods that exclude or privilege certain experiences and roles</li> </ul>
	<ul style="list-style-type: none"> <li>▪ Uses terms or images that elevate individuals' and communities' assets and resources</li> </ul> <p><b>Respects the ways in which people with lived experience choose to share their stories and input</b></p>	<ul style="list-style-type: none"> <li>▪ Uses terms or images that blame, victimize, degrade, and harm communities</li> </ul> <p><b>Shares stories from people with lived experience without their permission, especially in ways that stigmatize or stereotype</b></p>
 <b>Diverse group(s) of people with lived experience</b>	<p><b>Includes members of affected communities and focuses on experiences of those most impacted by systemic injustices</b></p> <ul style="list-style-type: none"> <li>▪ Considers people indirectly affected by an issue or injustice, such as parents and caregivers of people directly impacted by a policy or program</li> <li>▪ Includes people from communities that have not been traditionally engaged</li> <li>▪ Uses diverse mediums and strategies to advertise engagement opportunities</li> </ul> <p><b>Features authentic inclusion</b></p> <ul style="list-style-type: none"> <li>▪ Sensitively solicits and truly values diverse perspectives</li> </ul>	<p><b>Excludes members of communities affected by systemic injustices and overrepresents people from dominant culture(s), such as Western worldviews</b></p> <ul style="list-style-type: none"> <li>▪ Excludes others indirectly affected by an issue or injustice, such as parents and caregivers</li> <li>▪ Engages repeatedly the same people with lived experience or people from the communities or groups</li> <li>▪ Does not widely advertise engagement opportunities or uses strategies that are not accessible</li> </ul> <p><b>Tokenizes people with lived experience</b></p> <ul style="list-style-type: none"> <li>▪ Gives the appearance of including diverse perspectives when it does not or when engagement is not authentic</li> </ul>






- Expect awkward or uncomfortable conversations—this is common and necessary for building relationships!
- Make people feel more comfortable by relying on inclusive icebreakers and activities that allow for safe expression, where anyone can participate. It is good practice to share icebreaker questions or activities with participants in advance of the meeting.

Engagement component	 <b>Equitable engagement</b>	 <b>Inequitable engagement</b>
		<ul style="list-style-type: none"> <li>Assumes that a single experience is universal or asks a single person to speak for a group rather than for only themselves</li> </ul>
	<ul style="list-style-type: none"> <li>Think early about who is missing from the decision-making process. Have you included those most affected by a policy, program, or process? Have you considered those previously excluded?</li> <li>Involve communities affected by systemic injustices in identifying people to engage.</li> </ul>	
 <b>Equitable compensation and other benefits</b>	<b>Provides monetary compensation to people with lived experience who are not staff at a rate aligned with industry standards for other types of experts<sup>4</sup></b>	<b>Does not provide monetary compensation to people with lived experience who are not staff or does not compensate at a rate aligned with industry standards for other types of experts</b>
	<b>Offers benefits <i>in addition to</i> (not instead of) compensation for people with lived experience who are not staff, including nonmonetary benefits such as:</b> <ul style="list-style-type: none"> <li>Skills development (e.g., practice sessions)</li> <li>Professional development opportunities (e.g., training, conferences, networking, and mentoring)</li> <li>Authorship credit or acknowledgment in papers, reports, and presentations</li> <li>Ability to impact decision making directly</li> </ul>	<b>Does not offer benefits other than compensation, or offers <i>only</i> nonmonetary benefits to people with lived experience who are not staff</b> <ul style="list-style-type: none"> <li>Does not cover necessary supplemental expenses up front (e.g., requires people with lived experience to pay for hotel room deposits)</li> </ul>
	<ul style="list-style-type: none"> <li>Offer options for receiving compensation (e.g., gift cards, direct deposit).</li> <li>Ask people which nonmonetary benefits they prefer (e.g., specific training, connection to resources).</li> </ul>	
 <b>Orientation, background, and preparation for both people with lived experience and staff</b>	<b>Provides needed orientation, background, or preparation</b> <ul style="list-style-type: none"> <li>Clearly communicates requests, roles, expectations, and goals for an engagement</li> <li>Provides needed materials and information to people with lived experience, with ample lead time to permit full and effective participation</li> <li>Does not expect people with lived experience to have prior professional training</li> <li>Trains staff to recognize structural racism, bias, and privilege; to be trauma-informed; and to use strengths-based engagement methods</li> </ul>	<b>Provides inadequate orientation, background, or preparation</b> <ul style="list-style-type: none"> <li>Fails to communicate the engagement's request and goals</li> <li>Does not prepare people with lived experience or provide meeting materials or information with sufficient time to allow for meaningful consideration in advance</li> <li>Expects people with lived experience to have professional training as a prerequisite</li> <li>Does not train staff in key topics such as structural racism, bias, privilege, and trauma-informed and strengths-based engagement</li> </ul>
 <b>Accessibility</b>	<b>Engages people with lived experience in accessible ways</b> <ul style="list-style-type: none"> <li>Asks what resources people need to participate (e.g., child care, transportation, mental health services)</li> </ul>	<b>Engages people with lived experience in inaccessible ways</b> <ul style="list-style-type: none"> <li>Assumes or does not ask what resources people need to participate</li> <li>Schedules meetings at times, in places, or in ways that make it difficult for people with lived experience to participate (e.g., due to</li> </ul>

<sup>4</sup> Grant recipients must check with the funding agency before using federal dollars for this purpose.

Engagement component	 <b>Equitable engagement</b>	 <b>Inequitable engagement</b>
	<ul style="list-style-type: none"> <li>Offers a variety of days/times and ways to participate (e.g., orally in-person or virtually, in writing)</li> <li>Enables participation for those with varied abilities and access needs</li> </ul> <p><b>Uses accessible communication</b></p> <ul style="list-style-type: none"> <li>Uses plain language</li> <li>Ensures language access, such as providing translation and interpretation services in people’s primary language, and accommodations for people with disabilities</li> <li>Tailors content to relevant cultural contexts by recognizing diverse values, beliefs, and communication styles across cultures</li> <li>Moves at a pace that allows everyone to keep up</li> </ul> <p><b>Collaborates throughout the engagement to explore diverse engagement methods and implements lessons learned in future engagements</b></p>	<p>varied abilities or to technology, child care, transportation, or other life or time constraints)</p> <p><b>Uses inaccessible communication</b></p> <ul style="list-style-type: none"> <li>Uses acronyms, jargon, technical terms, or academic language</li> <li>Does not consider or ensure accessibility, including language access</li> <li>Does not tailor content to cultural context beyond dominant Western worldviews and excludes other worldviews</li> <li>Moves too quickly or at a pace that is overwhelming</li> </ul> <p><b>Does not seek feedback on preferred engagement methods or does not respond to people’s expressed preferences</b></p>
	<ul style="list-style-type: none"> <li>Ask people with lived experience how best to facilitate their engagement. What supports do they need to participate in a meaningful way? Would they be more comfortable participating if accompanied by others from their community?</li> <li>Offer meeting times outside of regular business hours.</li> <li>Offer a variety of accessible forms of engagement, if possible, such as a combination of written, oral, and virtual input.</li> <li>Provide sufficient time for engagement and move at a pace comfortable to participants. Have you included time for questions? Can you be flexible about the agenda if people want to allocate time differently?</li> <li>Review the tip sheet on equitable communication, available at <a href="https://aspe.hhs.gov/equity-tools">aspe.hhs.gov/equity-tools</a>.</li> </ul>	
 <b>Power dynamics and influence on decisions</b>	<p><b>Acknowledges up front the power dynamics between staff and people with lived experience and seeks to address them</b></p> <p><b>Prioritizes diversity within the group of people with lived experience and the staff who lead discussions, meetings, or events</b></p> <p><b>Provides realistic, meaningful opportunities to impact decisions</b></p> <ul style="list-style-type: none"> <li>Engages people as early as possible in the decision-making process</li> <li>Seeks to reflect accurately people’s input, not staff’s filtered version, and informs people about internal deliberations</li> <li>Follows up after an engagement to report the extent to which people’s feedback influenced decisions, and, if relevant, communicates why their input did not impact changes</li> </ul> <p><b>Engages people with lived experience as critical partners in designing, implementing, and evaluating research and programs</b></p> <p><b>Holds staff and leaders accountable to equity-related engagement goals</b></p>	<p><b>Ignores power dynamics between staff and people with lived experience</b></p> <p><b>Disregards the diversity and composition of people with lived experience and of staff</b></p> <p><b>Fails to seek meaningful input</b></p> <ul style="list-style-type: none"> <li>Engages people only in reaction to a specific request to do so partway through the decision-making process or seeks input when changes are impossible</li> <li>Ignores, omits, or revises the tone or intent of people’s input, and is secretive about internal deliberations</li> <li>Does not follow up after an engagement to report how staff used or will use people’s input</li> </ul> <p><b>Views people with lived experience as research subjects or program recipients rather than as co-creators or co-leaders</b></p> <p><b>Lacks accountability for staff and leaders on equity-related goals</b></p>

Engagement component	 <b>Equitable engagement</b>	 <b>Inequitable engagement</b>
	<ul style="list-style-type: none"> <li>▪ Tracks progress on equity-related goals, such as the extent to which people with lived experience influence decision making</li> <li>▪ Reports progress toward equity-related goals to people with lived experience</li> </ul>	<ul style="list-style-type: none"> <li>▪ Does not document progress on equity-related goals</li> <li>▪ Does not transparently and systematically report progress toward those goals</li> </ul>
	<ul style="list-style-type: none"> <li>▪ Share draft and final versions of products with people with lived experience to ensure they reflect their feedback and for their records.</li> <li>▪ Review considerations for engaging experts with lived experience found in learning sessions and tools on quantitative and intersectional analysis, available at <a href="http://www.aspe.gov/">www.aspe.gov/</a>.</li> </ul>	