

# WHY SOCIAL SCIENCE ?

## Because it helps us incorporate lived experience into health research

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There is a growing recognition in the scientific community that health research is richer when it incorporates the perspectives of those with lived experience.

What is [lived experience](#)? It is the unique expertise provided by individuals who have been directly affected by specific health issues. It could come from a patient or their caregiver, or from members of a community who have experienced something collectively, such as adverse health effects from contaminated drinking water. Those with lived experience hold powerful insights that can help improve health systems, research, and policy.

Traditionally, health research did not actively employ lived experience. Academic and medical expertise was seen as sufficient to address health concerns. Over time, it has become clear that other types of knowledge could help tackle complex health issues and those with lived experience are uniquely positioned to contribute the knowledge they have gained from their experiences. Involving people who have lived experience with specific health issues leads to more robust research—research that reflects what is important to communities, not just scientists. Academics and medical professionals can sometimes impose their views and biases on community members. Hearing directly from those with lived experience reduces these biases and embodies the principles of health equity and inclusion. Community members affected by a health challenge stand to benefit or to be harmed more than others by a study's outcomes. Therefore, it is important that their voices be heard as part of the process.

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However, intentionally including those with lived experience at the start of a project requires researchers to think differently about what sorts of expertise are important and how to make sure they are considered. Social science provides a way forward through its work on key concepts that allow researchers to interact with lived experience and methodologies for gathering data from community members.

Cultural competence, intersectionality, and personal narratives are examples of social science concepts that provide frameworks that help researchers understand, interpret, and integrate the complexities of individual lives into health studies. Cultural competency addresses one's ability to work with people from different cultures and with different life views. Intersectionality is the recognition that people associate with multiple identities (for example, a woman may be a patient, but she is also Asian American, a member of her church, and a caregiver). The differing positions of power, or lack thereof, naturally shape her experiences. Personal narratives are the stories that individuals tell about their own lives. They give people a way to communicate their unique perspectives and make sense of their world. Each of these social science concepts helps researchers better navigate the inclusion of lived experience into health research.

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Additionally, social science fields like anthropology, sociology, and psychology offer advanced qualitative methodologies that can be used to collect perspectives from those who have first-hand knowledge of health issues. For example, open-ended surveys allow researchers to hear from community members in their own words. Community-based participatory research creates a level playing field and gives community members and researchers equal input. Focus groups provide an opportunity for a conversation among participants and allow the facilitator to tailor questions to draw out information that might otherwise be missed. These methodologies have been instrumental in helping researchers collect meaningful data about people's lives.

***“The ability to humanize health research benefits everyone.”*** Like other institutions, the Health and Medicine Division of the National Academies of Sciences, Engineering, and Medicine has been working to include expertise from patients and community members who are directly affected by the policy research we do.

In our 2022 study on [Per-and Polyfluoroalkyl Substances \(PFAS\) exposure, testing, and clinical follow up](#), we engaged liaisons from across the country to connect to communities experiencing a high burden of PFAS to help inform the committee's recommendations. For a 2022 workshop about [methadone treatment for opioid use disorder](#), we framed the discussion by opening the event with remarks from individuals who have used methadone treatment. As part of a 2023 workshop on the train derailment in [East Palestine](#), Ohio, we organized public listening sessions to document important research questions from the community. And when we launched a study on [Amyotrophic Lateral Sclerosis \(ALS\)](#) in 2023, we sought nominations of people living with the disease or carriers of gene C9orf72 and included them as members of the expert committee. In each of these cases, we carefully tailored our approach for including lived experience to derive the most significant input possible.

Including lived experience is not appropriate for every National Academies study, but when it is, academics are exposed to different types of knowledge, individuals have input into research projects that impact their lives, and the activities we facilitate are more informed and inclusive. As we continue to develop best practices and refine our approaches, we will look to social science as a guiding light. The ability to humanize health research benefits everyone.



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