

Teaching & Researching the Camp Fire Guiding Principles

We recognize the fact that to serve the recovery efforts of those impacted by the Camp Fire, it is crucial that we acknowledge and honor the principles of Community Based Participatory Research: that those who live in a community are experts in their experience and must be central in all decision making related to their recovery.

To this end, we will make every effort to adhere to the following principles as we are teaching, researching and working on the Ridge:

Prior to consent, prospective participants should be asked, to the extent feasible, about unmet needs and provided assistance including referrals and resources to reduce risk and maximize benefit.

In the immediate aftermath of a disaster, survivors are often left behind with acute physical and mental health needs. Additionally, disasters can cause chronic impacts that impair social and economic stability including loss of employment and the dissolution of social networks. It is imperative that the essential needs of community members are met for them to have adequate capacity to make a voluntary decision about participation in projects with the University.

Close monitoring of the consent process is key to address any misconceptions about the research.

When applicable, research teams and the Institutional Review Board (IRB) should ensure close monitoring of the consenting process during recruitment of participants on the Ridge. In disaster studies, especially in the immediate aftermath of a disaster. Research teams must establish a standard plan (e.g., which may include a capacity or competence assessment screening questionnaire) for determining the decision-making ability of disaster-affected research participants to provide informed consent. As a precaution to eliminate confusion concerning the exchange of disaster aid for participating in research, consent forms may include a section requiring the participants to initial for indication they understand that they are participating in research and that their participation in the study is independent of disaster aid administered by local, state, or federal agencies or other entities.

Post-fire research and teaching should be encouraged for members of vulnerable groups that are underrepresented in the disaster research literature such as women, racial/ethnic minorities, and elderly and disabled populations.

Researchers should develop new strategies to overcome the perceived barriers to the conduct of disaster research with groups that require special protections or who may have unique vulnerabilities. Valuable, informative research data may be lost if studies do not include these populations in their disaster studies. This is especially true when conducting research to assess behavioral and mental health outcomes. Indeed, there is mounting evidence that members of

¹ Recommendations adapted from Pakenham, J., Rosselli, R., Ramsey, S., Taylor, H., Fothergill, A., Slutsman, J., & Miller, A. (2017). Conducting Science in Disasters: Recommendations from the NIEHS Working Group for Special IRB Considerations in the Review of Disaster Related Research. *Environmental Health Perspectives*, 125(9), 094503.

vulnerable groups may experience significant long-term mental and physical consequences following disaster events.

Justice demands that research be carried out for the benefit of the population as a whole; therefore, systematic exclusion of protected or vulnerable groups from disaster research studies should be avoided. Failure to include these groups leaves a knowledge gap in our understanding of the impact of disasters across the entire population.

Minimize participant burden associated with multiple duplicative studies in the field through coordination and communication of efforts.

Survivors of disasters are often approached by many investigators, all seeking the same or similar information. This can result in survey and specimen collection fatigue and an overall increase in participant burden. A coordinated effort among researchers and funders could reduce duplication.

All research should have a plan for the timely dissemination of actionable research results back to key stakeholders.

One of the principles of ethical research is to provide results and feedback to stakeholders, and disaster research is no different in that regard. IRBs should require researchers to develop a dissemination plan for the results that clearly describes how the data will be reported back to participants and the community throughout the life cycle of the study. The plan must ensure a timely report back and should consider specific entities such as community groups and health educators that can help translate scientific findings into lay language. Methods of dissemination should be carefully considered to optimize information exchange with the community and may include town hall forums, newsletters, and use of social media.