

CIAPM Guidance on Authentic Research-Community Partnerships

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A significant mission of the California Initiative to Advance Precision Medicine (CIAPM) is to reduce health disparities, in part by orienting the vast health research infrastructure and the emerging field of Precision Medicine toward addressing inequitable medical challenges that persist across time and geographies. In order to foster research outcomes that address the needs and concerns of patients, family members, and health care providers, authentic research-community partnerships are critical.

According to the Institute of Medicine, community-based participatory research enhances community understanding of the issues under study and improves researchers' ability to understand community priorities, the importance of addressing community priorities, and the need for culturally sensitive approaches and outreach.¹ Part of ensuring the success of CIAPM in demonstrating the promise of Precision Medicine is ensuring vital research results are informed by and shared with those who need it most and in ways that are timely, relevant, and meaningful.

This Guidance aims to provide resources for researchers, communities, clinicians, and other project partners to encourage high quality, interactive, and proactive stakeholder models, where patients and families are represented in the governance, design, conduct, dissemination, and evaluation of CIAPM-funded research demonstration projects.

To facilitate cross-sector partnerships, CIAPM created the [California Precision Medicine Asset Inventory](#), an online, interactive mapping tool that provides a dynamic view of private, public, and nonprofit entities working within areas relevant to Precision Medicine and community health. All researchers, patient advocacy and community organizations, health care providers, and others are invited to submit their basic information to be included in the Inventory. Information may be included by submitting the [Asset Inventory Form](#).

Resources for authentic research-community partnerships

Successful CIAPM demonstration project proposals will exemplify a thoughtful strategy to developing and facilitating authentic cross-sector partnerships. The following resources are freely available and recommended:

- [The Practical Playbook II: Building Multisector Partnerships That Work](#), Edited by J. Lloyd Michener, Brian C. Castrucci, Don W. Bradley, Edward L. Hunter, Craig W. Thomas, Catherine Patterson, and Elizabeth Corcoran; published May 21, 2019 by Oxford University Press; [Download](#)
- "Patient and Public Involvement in Research: Enabling Meaningful Contributions," Written by Sarah Ball, Amelia Harshfield, Asha Carpenter, Adam Bertscher, and Sonja Marjanovic; published in 2019 by RAND Corporation; [Download](#)
- "Precision Medicine Initiative Cohort Program – Building a Research Foundation for 21st Century Medicine Report," published September 17, 2015, p. 38-44. [Download](#)

¹ Rosenstock L, Hernandez L, Gebbie K, eds. *Who Will Keep the Public Healthy? Educating Public Health Professionals for the 21st Century*. Washington, DC: National Academies Press; 2003

- “Chapter 1. The vision, valley, and victory of community engagement.” Written by Loretta Jones, Kenneth Wells, Keith Norris, Barbara Meade, and Paul Koegel; published Autumn 2009; *Ethnicity & Disease*, 19(4 Suppl 6), S6–7. [Download](#)
- “Applying a community-based participatory research framework to patient and family engagement in the development of patient-centered outcomes research and practice.” Written by Simona C. Kwon, Shiv Darius Tandon, Nadia Islam, Lindsey Riley, and Chau Trinh-Shevrin; published October 2018 in *Translational Behavioral Medicine*, 8;8(5):683-691; [Download](#)
- Principles of Community Engagement, Second Edition, Written by the Clinical and Translational Science Awards Consortium Community Engagement Key Function Committee Task Force on the Principles of Community Engagement; published June 2011 by the National Institutes of Health; [Download](#)
- “Community Engagement in Research: Frameworks for Education and Peer Review,” Written by Syed M. Ahmed and Ann-Gel S. Palermo, published August 2010 in the *American Journal of Public Health*, 100(8): 1380-1387; [Download](#)

Resources on Adverse Childhood Experiences

The Office of the California Surgeon General has developed a website with many resources on ACEs that will become publicly available on December 4, 2019: www.acesaware.org.

Health Disparity Research Resources

Applicants for CIAPM funds are encouraged to learn about health disparities and establish new collaborations through the California Precision Medicine Asset Inventory. Additional resources are available via the following links:

- National Institute on Minority Health and Health Disparities Community-Based Participatory Research Initiative, <https://www.nimhd.nih.gov/programs/extramural/community-based-participatory.html>
- Health Resources and Services Administration (HSRA) Office of Minority Health: Search for health disparity programs at <https://www.hrsa.gov/index.html>.
- U.S. Centers for Disease Control and Prevention Office of Minority Health and Health Equity, <https://www.cdc.gov/healthequity/index.html>.
- National Institutes of Health (NIH) Research Portfolio Online Reporting Tool (NIH RePORTER): Search for NIH awards at <https://projectreporter.nih.gov/reporter.cfm>.
- National Library of Medicine, NIH, PubMed: Search for investigators publishing studies on health disparities at <https://www.ncbi.nlm.nih.gov/pubmed>.
- U.S. Department of Education: Search for institutions that may have increased access to disproportionately affected populations at <https://www2.ed.gov/about/offices/list/ocr/edliteminorityinst.html>.
- National Coalition for LGBT Health: For more information on programs focused on lesbian, gay, bisexual, and transgender (LGBT) research, policy, education, and training, search <http://www.healthlgbt.org>.
- Indian Health Services, <https://www.ihs.gov/>.
- National Alliance for Hispanic Health, <https://www.healthyamericas.org/>.
- National Medical Association, <https://www.nmanet.org/>.
- National Rural Health Association, <https://www.ruralhealthweb.org/>.
- California Department of Public Health Office of Health Equity, <https://www.cdph.ca.gov/Programs/OHE/Pages/OfficeHealthEquity.aspx>.