

**Health Equity in Research, Evaluation,  
and Other Data-gathering Activities  
Phase 1: Formative Research**

**November 2022**

**Office of the Institutional Review Board  
Los Angeles County Department of Public Health**



**LOS ANGELES COUNTY  
BOARD OF SUPERVISORS**

**Hilda L. Solis**, First District

**Holly Mitchell**, Second District

**Sheila Kuehl**, Third District

**Janice Hahn**, Fourth District

**Kathryn Barger**, Fifth District

**LOS ANGELES COUNTY  
DEPARTMENT OF PUBLIC HEALTH**

**Barbara Ferrer**, PhD, MPH, MEd, Director

**Muntu Davis**, MD, MPH, Health Officer

**Megan McClaire**, MSPH, Chief Deputy Director

**Paul Simon**, MD, MPH, Chief Science Officer

**INSTITUTIONAL REVIEW BOARD (IRB)**

**HEALTH EQUITY INITIATIVE**

**RESEARCH TEAM**

**Alysia Kwon**, ScM, Director

Office of the Institutional Review Board

**Paul Camarena**, MPH, IRB Analyst

**Will Nicholas**, PhD, MPH, IRB Chair

**Walt Senterfitt**, PhD, RN, MPH, IRB Chair Emeritus

**Suggested Citation:** Camarena, Paul; Kwon, Alysia; Nicholas, Will; Senterfitt, Walt. Los Angeles County Department of Public Health, Office of the Institutional Review Board. Health Equity in Research, Evaluation, and Other Data-gathering Activities Phase 1: Formative Research, November 2022.

# Introduction

With health disparities coming into sharp focus during the COVID-19 pandemic, addressing equity in public health research is essential now more than ever. Although advancing health equity is increasingly emphasized as a central goal of public health practice, the role that entities such as Institutional Review Boards (IRBs) play in advancing health equity is not clearly defined.<sup>1-6</sup> There is a growing body of literature suggesting that the value of IRBs in promoting health equity has been underrecognized and their authority underutilized.<sup>7-10</sup> As independent oversight entities that review research activities for compliance with ethical standards rooted in the principles of the Belmont Report, IRBs are in a unique position to ensure that research is conducted in an equitable manner. Addressing health equity in the research field can impact both the soundness of research and related activities,<sup>\*</sup> and ultimately the health outcomes that may result from the application of research findings in the real world.<sup>11</sup> In this report, we will describe our efforts to foster an environment that prioritizes health equity in research and related data-gathering activities by leveraging our regulatory role as the IRB of record for the Los Angeles County (LAC) Department of Public Health (DPH).

## Background

Pursuing health equity means striving for the highest possible standard of health for all people and giving special attention to the needs of those at greatest risk of poor health, based on certain social conditions.<sup>12-13</sup> DPH further defines health equity as “when everyone has access to the goods, services, resources, and power they need for optimal health and well-being.”<sup>14</sup> Health equity can thus be understood as an ethical concept, based on principles of social justice, that acknowledges the often disproportionate impact of contextual, population-level factors on individual-level health outcomes.<sup>15</sup> The root causes of health inequity can be directly linked to a failure to adequately address population-level factors such as the physical, social and policy

---

\* “Related activities” refers to any process that involves collecting data from or about individuals other than that related to provision of clinical care or conducting statutorily mandated surveillance and disease or environmental investigation, including but not limited to the following: activities that may be considered “practice” or otherwise not research, program evaluation, quality assurance and improvement, special surveillance and needs assessments.

environments within which health is realized.<sup>16-20</sup> Identifying where to intervene effectively to improve health equity requires an acknowledgement and understanding of the underlying complex causal mechanisms.<sup>16-20</sup> A review of the literature finds strong support for multi-sectoral efforts informed by health impact and community needs assessments, structural and policy analyses, as well as data on trends, patterns and community assets that can be used to mobilize action.<sup>21-25</sup>

The ability to measure and regularly report health inequities is fundamental to achieving health equity goals. Progress in this area has been hampered by several factors, including low levels of representation in health-related research among racial/ethnic minority populations.<sup>26-29</sup> The need for increased ethnic minority representation in public health research is paramount to ensure that study findings are applicable to the increasingly diverse populations that make up the United States.<sup>26-29</sup> In the United States and globally, “participant enrollment in research has not reflected the demographic composition of the general population, those affected by the health conditions being studied, or those for whom the investigational product is intended, with racial and ethnic minorities and the young and the elderly being consistently underrepresented.”<sup>9</sup> A review of the literature reveals that issues such as a lack of community engagement, study sampling and recruitment inequities, lack of language and cultural equity in study materials, and cost considerations pose significant barriers to research participation for underrepresented minorities.<sup>26-29</sup>

Health equity is a lens through which one should view all research activities and outcomes.<sup>30</sup> All elements of the research process must embrace the principles of health equity in order to produce the types of generalizable findings that can better inform action at all levels.<sup>11,26-29</sup> As Strauss and colleagues note, “the requirements of justice cannot be met...when there is de facto exclusion of understudied populations.”<sup>9</sup> But research activities exist within a larger environment that influences what type of research is undertaken and how that research is conducted. The IRB is a major stakeholder in the research environment as it is the body charged with protecting human subjects involved in research activities and ensuring that research is conducted in an ethical manner. Although the IRB focuses on compliance with the principles outlined in the

Belmont Report (justice, beneficence, and respect for persons), equity considerations are essential to fully comply with the intent of those principles.<sup>8</sup> Furthermore, it is important to examine the biases that may be hidden in research processes as they may be inadvertently promoting inequities.<sup>31</sup>

To gain a better understanding of health equity within the Los Angeles County research landscape, the DPH IRB is implementing a *Health Equity Initiative (HEI)*. In phase 1 of the *HEI*, IRB staff conducted key informant interviews with a select group of local research and evaluation experts. For phase 2 of the *HEI*, based on the data gleaned from the interviews, a survey will be developed and administered to a larger sample to assess general attitudes, beliefs, and practices regarding health equity in research. Informed by the interview and survey data, *HEI* efforts will culminate with the development of an internal DPH IRB health equity policy that will 1) serve as a roadmap for DPH researchers to incorporate health equity components into their research and other data-gathering activities; and 2) ensure accountability in the ongoing process of addressing health equity in research by integrating the collection of health equity metrics into the DPH IRB review process.

## Methods

In May and June 2022, the research team conducted key informant interviews to gain insight into perceptions of and experiences with health equity in research. The research team identified fourteen individuals with known involvement in research and other data-gathering activities or health equity work within Los Angeles County. Selection of these informants was performed by senior IRB members with over 25 years of experience interacting with local researchers and research project managers.

Informants were limited to Los Angeles County as the research team already had established contacts within the County and wanted to collect data that was specific to the County given the interviews were to inform a DPH IRB policy.

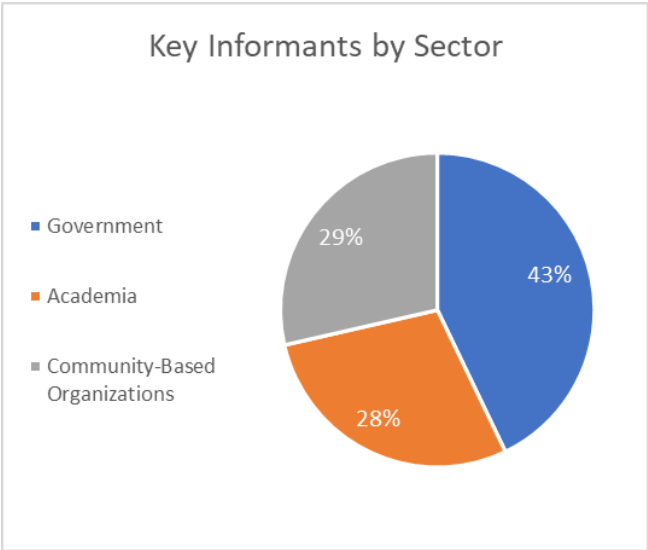
The research team conducted key informant interviews with the researchers using a Key Informant Interview Script as a guide. Interviews consisted of eight questions that asked about health equity as it relates to the research and data-gathering environments within which the interviewees conduct their work. The approximate duration of each interview was between 30 and 60 minutes and interviews were conducted via the Teams or Zoom platforms, or by telephone in one case due to technical difficulties. Interviews were recorded with permission of the informants.

Two analysts completed a content analysis of the data collected from the key informant interviews and identified 6 domains representing key themes from among the responses. An adjudicator was not needed as the data were generally in concurrence making it easier to extract major themes.

# Results

Key informants represented government, academia, and community-based organizations (Figure 1). Key informant interview data yielded the following thematic domains: 1) defining health equity; 2) health equity in research; 3) barriers to health equity in research; 4) measuring health equity in research; 5) organizational support for health equity; 6) funding for addressing health equity in research.

Figure 1



### Defining Health Equity

*“Sometimes the things that people experience have nothing to do with where they are in that moment, but a lot to do with the history of how they got there....And sometimes that can’t always be assessed...neatly and maybe that’s the anecdotal or the qualitative part of research that resonates sometimes much better with trying to understand equity and Health Equity Issues than just the data....Quantitative data is important but it is really in those stories where we really learn.”*

At the beginning of the interview, informants were asked whether DPH’s definition of health equity -- *“when everyone has access to the goods, services, resources, and power they need for optimal health and well-being”* -- resonated with them and whether they would change or add anything to the definition. All informants agreed that this definition of health equity resonated with them, although several informants noted that there were certain elements they would add to the definition. Two informants acknowledged the importance of the word “power” in the definition with one informant stating they “appreciate the recognition that power and health are related.” Two informants felt that DPH’s definition omits concepts of justice and fairness, while another informant suggested that any discussion of health equity should give voice to people who are most affected by the issues that are being studied. One informant stated that they would like the definition to mention the elimination of health disparities in outcomes. Lastly, one informant pointed out that the concept of health

equity is often too closely associated with healthcare and health outcomes and any definition of health equity needs to make clear that health equity intersects all aspects of health, including social determinants of health.

### Health Equity in Research

*“Did you check in with community members and a diverse set of community members? Because I think what happens oftentimes is we assume that one organization has a pulse on an entire community, but they may only interact with a segment of it.”*

Informants were next asked to describe strategies that the research field<sup>†</sup> can implement to help promote health equity. Seven informants agreed that the research field should do a better job of involving community members and community-based organizations throughout the research process - from the development of the research question and study design to the dissemination of results. Among those seven informants, four highlighted the value of and need for researchers to integrate principles of Community-Based Participatory Research (CBPR) into their work. Five informants noted that the research field must do a better job with recruitment and retention of under-served communities by offering study documents that are in appropriate languages and reading levels. Three informants suggested that improving diversity within research teams - across multiple demographic domains such as age, race/ethnicity, LGBTQI+/Gender Identity, disability status, and relative wealth/socioeconomic status - is one way to help alleviate challenges in recruiting from historically under-served communities.

### Barriers to Health Equity in Research

*“Trust in the community is probably number one....Oftentimes research teams don't look like or live in or represent the communities that they're assessing and so that creates a barrier...which is why I think it's also important to have a community based participatory action part of [research]....When you're engaging residents to help in the design, the*

---

<sup>†</sup> “Research field” refers to all the stakeholders that are involved in the implementation of research and related activities including but not limited to: researchers and research staff, organizations that conduct research, organizations that fund research, government entities that regulate research



*implementation and then the analysis of it - it just lends more credibility to the community.”*

Informants were asked to name the three biggest barriers to addressing health equity in research. There was consensus among eight informants that a lack of trust between the community and the research field is a major barrier. Eight informants pointed to inadequate funding and resources as another major barrier, while six informants responded that a lack of research study materials in appropriate languages and reading levels for their intended target audiences is another barrier. One informant noted that larger incentives are needed to compensate participants for time, travel expenses, childcare, and time off from work; however, in this researcher’s experience larger incentives were considered “coercive” by one IRB. Five informants suggested that the current research agenda can be a barrier as it is too often driven by disease and health outcomes while less attention is given to structural determinants of health such as access to quality healthcare, access to healthy foods, and access to safe and affordable housing.

### Measuring Health Equity in Research

*“Measure what you value.”*

To get a better understanding for what guidance our IRB can provide to researchers who are investigating health equity, informants were asked to provide indicators that can be used to measure health equity and the extent to which equity is being addressing in a research project. Four informants mentioned that the degree to which a participant sample is representative of the target population is one indicator that can be used to measure health equity. Four informants added that the degree to which the research team (i.e., all persons carrying out data-gathering activities) is representative of the target population is another indicator of health equity. Four informants identified the degree or level of community engagement as an indicator of health equity while two informants noted that the availability of materials in appropriate languages and reading levels can also be used to measure health equity. Five informants suggested that research projects should include evaluation components that directly assess whether the research protocol was carried out in a manner consistent with principles of health equity. Lastly, two

informants mentioned the importance of conducting data analyses in such a manner that allows findings to be reported with disaggregated data so that the results are more relevant and meaningful to diverse communities such as those in Los Angeles County.

### Organizational Support for Health Equity

*“I also think it's important for people to have sorted their own self-awareness. I think this is true for everybody working in public health or public policy. It's sort of like who they are, and what they bring to the table, because it then helps them to be able to figure out sort of how they have connections to the people there.”*

While there was agreement among all informants that their organizations valued health equity, the extent to which the informants felt their organizations demonstrated that value varied. Six informants noted that their organizations provided support for health equity in the form of staff, training, or translation services. Conversely, five informants noted that their organizations needed to do a better job of providing staffing and training support. Eight informants responded that organizations should provide training related to community engagement in research and conducting research with diverse populations. Five informants responded that education regarding how to conduct research equitably should be provided. Four informants responded that general research principles and training should be provided while three informants noted that training should be offered on the structural determinants of health.

### Funding for Health Equity

*“...the culture of scientific review is really focused on...trying to make things about medications or diseases instead of the underlying material conditions of people's lives.”*

Informants noted that existing research funding mechanisms can be cumbersome, prohibitive, and often insufficient to address health equity. Seven informants agreed that more funding must be made available to researchers for investigating issues related to health equity as, according to one informant, budgets have remained largely unchanged while costs have increased. Three informants noted that funders should consider including health equity requirements in their

funding proposals so that grantees can be held accountable for fulfilling these requirements. All fourteen informants were receptive to the idea of a mini-grant proposal that would provide supplementary funds for projects that address health equity, although one informant noted that such programs can exacerbate funding disparities since seasoned researchers are typically better experienced and successful in accessing such funds. Another informant noted that funding cycles are too short to address health equity which incentivizes a focus on short-term (e.g., 2-3) predictors and outcomes rather than a lifecycle approach that takes into account structural factors such as early education and childhood interventions. Funders also tend to focus on specific predictors or outcomes that change with each cycle and current trends in the scientific community and political climate.

## Conclusions

The DPH IRB's HEI key informant interviews yielded rich data from local experts. The overarching finding that community engagement is key to achieving health equity highlights the importance of researchers being able to make connections with the community and partner with community-based organizations. Involving community members and enabling them to voice their opinions and concerns about research and other data-gathering activities that affect them can be instrumental in overcoming the pervasive lack of community trust in the research field, which was identified as a major barrier to addressing health equity. Such an approach to research and related activities creates a more equitable power dynamic that can be leveraged for sustainable and long-term partnerships.

Equitable recruitment can be addressed not only by involving the community in recruiting from their social networks but by providing researchers with training and financial support for translations and staffing: multi- or bi-lingual researchers who can recruit, obtain informed consent, and administer surveys or other forms of data collection. Findings from the key informant interviews suggest that the IRB can play a role in promoting health equity by offering consultations and education on how to incorporate principles of health equity in research, e.g., a checklist of health equity considerations to hold researchers accountable for ensuring that they

have successfully incorporated health equity principles in their projects. Such a checklist can address issues such as the relevance and public health importance of the research question, whether the sample selection and recruitment are equitable, language and reading level accessibility, and the level of community engagement throughout the research process.

## Next Steps

The findings of the key informant interviews will inform Phase 2 of the *HEI*, an annual survey administered to a larger sample to assess general attitudes, beliefs, and practices regarding health equity in research. The sample will be derived from referrals from the key informants, an internet search of local academic, governmental and community-based organizations and referrals from the DPH Center for Health Equity, an entity devoted to furthering DPH's mission of achieving health equity in the County of Los Angeles. Informed by the interview and survey data, *HEI* efforts will culminate with the development of an internal DPH IRB health equity policy that will 1) serve as a roadmap for DPH researchers to incorporate health equity components into their research and other data-gathering activities; and 2) ensure accountability in the ongoing process of addressing health equity in research by integrating the collection of health equity metrics into the DPH IRB review process.

## References

1. Chandra A, Acosta J, Carman KG, Dubowitz T, Leviton L, Martin LT, Miller C, Nelson C, Orleans T, Tait M, Trujillo M, Towe V, Yeung D, Plough AL. Building a National Culture of Health: Background, Action Framework, Measures, and Next Steps. *Rand Health Quarterly*. 2017 Jan 13;6(2):3.
2. Dean HD, Williams KM, Fenton KA. From theory to action: applying social determinants of health to public health practice. *Public Health Rep*. 2013;128 Suppl 3(Suppl3):1-4.
3. Komro KA, Lang DL, Walker ER, Harper PD. Integrating Structural Determinants Into MPH Training of Health Promotion Professionals. *Am J Public Health*. 2018 Apr;108(4):477-479. doi: 10.2105/AJPH.2018.304309. PMID: 29513578; PMCID: PMC5844413.
4. Östlin P, Schrecker T, Sadana R, Bonnefoy J, Gilson L, Hertzman C, Kelly MP, Kjellstrom T, Labonté R, Lundberg O, Muntaner C, Popay J, Sen G, Vaghri Z. Priorities for research on

- equity and health: towards an equity-focused health research agenda. *PLoS Med.* 2011 Nov;8(11):e1001115. doi: 10.1371/journal.pmed.1001115. Epub 2011 Nov 1. PMID: 22069378; PMCID: PMC3206017.
5. Knight EK. Shifting public health practice to advance health equity: recommendations from experts and community leaders. *J Public Health Manag Pract.* 2014 Mar-Apr;20(2):188-96. doi: 10.1097/PHH.0b013e31829959fb. PMID: 24002297.
  6. WHO (World Health Organ.), Comm. Soc. Determ. Health. 2008. Closing the gap in a generation: health equity through action on the social determinants of health. Fin. Rep., Comm. Soc. Determ. Health, WHO, Geneva.  
[https://www.who.int/social\\_determinants/thecommission/finalreport/en/](https://www.who.int/social_determinants/thecommission/finalreport/en/)
  7. Phelan M. Institutional Review Boards Must Address the Ethics of Inclusion in Clinical Research. *American Association for the Advancement of Science News Brief.* 2021 Mar 19.
  8. Parekh J, Ramos MF. Racial Equity Considerations and the Institutional Review Board. *Child Trends.* 2020 March 11.
  9. Strauss DH, White SA, Bierer BE. Justice, diversity, and research ethics review. *Science.* 2021 Mar 19;371(6535):1209-1211.
  10. Anderson, Jane. IRB Role Seen as Critical in Promoting Diversity and Equity in Research. Report on Research Compliance, HCCA. Volume 18, Number 8. July 22, 2021. Accessed on 4/7/22.
  11. McNulty M, Smith JD, Villamar J, Burnett-Zeigler I, Vermeer W, Benbow N, Gallo C, Wilensky U, Hjorth A, Mustanski B, Schneider J, Brown CH. Implementation Research Methodologies for Achieving Scientific Equity and Health Equity. *Ethn Dis.* 2019 Feb 21;29(Suppl1):83-92.
  12. Braveman P. What are health disparities and health equity? We need to be clear. *Public Health Rep.* 2014;129 Suppl 2(Suppl 2):5-8A.
  13. Penman-Aguilar A, Talih M, Huang D, Moonesinghe R, Bouye K, Beckles G. Measurement of Health Disparities, Health Inequities, and Social Determinants of Health to Support the Advancement of Health Equity. *J Public Health Manag Pract.* 2016 Jan-Feb;22 Suppl 1(Suppl 1):S33-42. doi: 10.1097/PHH.0000000000000373. PMID: 26599027; PMCID: PMC5845853.
  14. Call to Action: Supporting a Movement for Fair and Just Health Outcomes, Action Plan 2018-2023. LAC-DPH Center for Health Equity website. Accessed at <http://publichealth.lacounty.gov/centerfortheequity/Equity.html> on March 3, 2021.
  15. Peter F. 2001. Health equity and social justice. *J. Appl. Philos.* 18:159–70
  16. Woolf SH. 2017. Commentary: progress in achieving health equity requires attention to root causes. *Health Aff.* 36:984–91
  17. Heller J, Givens ML, Yuen TK, et al. Advancing efforts to achieve health equity: equity metrics for health impact assessment practice. *Int J Environ Res Public Health.* 2014;11(11):11054-11064.
  18. Lee J, Schram A, Riley E, Harris P, Baum F, Fisher M, Freeman T, Friel S. Addressing Health Equity Through Action on the Social Determinants of Health: A Global Review of Policy

- Outcome Evaluation Methods. *Int J Health Policy Manag.* 2018 Jul 1;7(7):581-592. doi: 10.15171/ijhpm.2018.04. PMID: 29996578; PMCID: PMC6037500.
19. Lynch JF, Perera IM. 2017. Framing health equity: US health disparities in comparative perspective. *J. Health Politics Policy Law* 42:803–39
  20. Dover DC, Belon AP. The health equity measurement framework: a comprehensive model to measure social inequities in health. *Int J Equity Health.* 2019 Feb 19;18(1):36. doi: 10.1186/s12939-019-0935-0. Erratum in: *Int J Equity Health.* 2019 Apr 23;18(1):58. PMID: 30782161; PMCID: PMC6379929.
  21. Jones NL, Breen N, Das R, Farhat T, Palmer R. Cross-cutting Themes to Advance the Science of Minority Health and Health Disparities. *Am J Public Health.* 2019;109(S1): S21-S24.
  22. Remiker M, Sabo S, Jimenez D, Samarron Longorio A, Chief C, Williamson H, Teufel-Shone N. Using a Multisectoral Approach to Advance Health Equity in Rural Arizona: Community-Engaged Survey Development and Implementation Study. *JMIR Form Res.* 2021;5(5)e25577.
  23. Liburd LC, Hall JE, Mpofu JJ, Williams SM, Bouye K, Penman-Aguilar A. Addressing Health Equity in Public Health Practice: Frameworks, Promising Strategies, and Measurement Considerations. *Annu Rev Public Health.* 2020 Apr 2;41:417-432. doi: 10.1146/annurev-publhealth-040119-094119. Epub 2020 Jan 3. PMID: 31900101.
  24. Natl. Acad. Sci. Eng. Med., Health Med. Div. 2017. *Communities in Action: Pathways to Health Equity*, ed. A Baciu, Y Negussie, A Geller, JN Weinstein. Washington, DC: Natl. Acad. Press
  25. Shankardass K, Solar O, Murphy K, Greaves L, O’Campo P. 2012. A scoping review of intersectoral action for health equity involving governments. *Int. J. Public Health* 57:25–33.
  26. Levkoff S, Sanchez H. Lessons learned about minority recruitment and retention from the Centers on Minority Aging and Health Promotion. *Gerontologist.* 2003 Feb;43(1):18-26.
  27. Yancey AK, Ortega AN, Kumanyika SK. Effective Recruitment and Retention of Minority Research Participants. *Annu Rev Public Health.* 2006;27:1-28.
  28. Brown DR, Fouad MN, Basen-Engquist K, Tortolero-Luna G. Recruitment and retention of minority women in cancer screening, prevention, and treatment trials. *Ann Epidemiol.* 2000 Nov;10(8 Suppl):S13-21. doi: 10.1016/s1047-2797(00)00197-6. PMID: 11189088.
  29. Ness RB, Nelson DB, Kumanyika SK, Grisso JA. Evaluating minority recruitment into clinical studies: how good are the data? *Ann Epidemiol.* 1997 Oct;7(7):472-8. doi: 10.1016/s1047-2797(97)00080-x. PMID: 9349914.
  30. Castillo EG, Harris C. Directing Research Toward Health Equity: a Health Equity Research Impact Assessment. *J Gen Intern Med.* 2021 Sep;36(9):2803-2808. doi: 10.1007/s11606-021-06789-3. Epub 2021 May 4. PMID: 33948804; PMCID: PMC8096150.
  31. Garner L, Yedlin NC, Salopek J. “How Can We Dismantle Health Equity Barriers in Research?”. *Health Affairs Blog.* 2020 Feb 5.