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Choosing Health Equity:
Understanding Decision Points in Research

Erin Mackay, Managing Director for Health Justice
Dani Gillespie, Health Justice Policy Associate
Sinsi Hernández-Cancio, Vice President for Health Justice

Systemic racism is a fundamental, multilevel driver of pervasive health inequities in the United States. Racism threatens our nation's health so deeply that the American Medical Association, the American Public Health Association, and a growing list of U.S. cities, counties, and states have declared racism a public health crisis.

Effectively advancing health equity will require dedicated efforts to generate and apply an evidence base that reflects the multilayered impacts of racial and gender discrimination, and other intersecting structures of disadvantage. Only then will we eliminate health inequities and close the gaps between communities of color and white communities.

Health care stakeholders cannot fix what they do not see. This tool is designed to surface the numerous decision points that exist in the cycle of generating and applying evidence to create the policies, programs, and practices that will improve health for everyone. At every step of this process, researchers, decisionmakers, and advocates make multiple decisions – whether they are conscious of them or not. Each of these decision points has significant implications on whether they will advance health equity, or rather perpetuate racial, ethnic, and gender inequities.
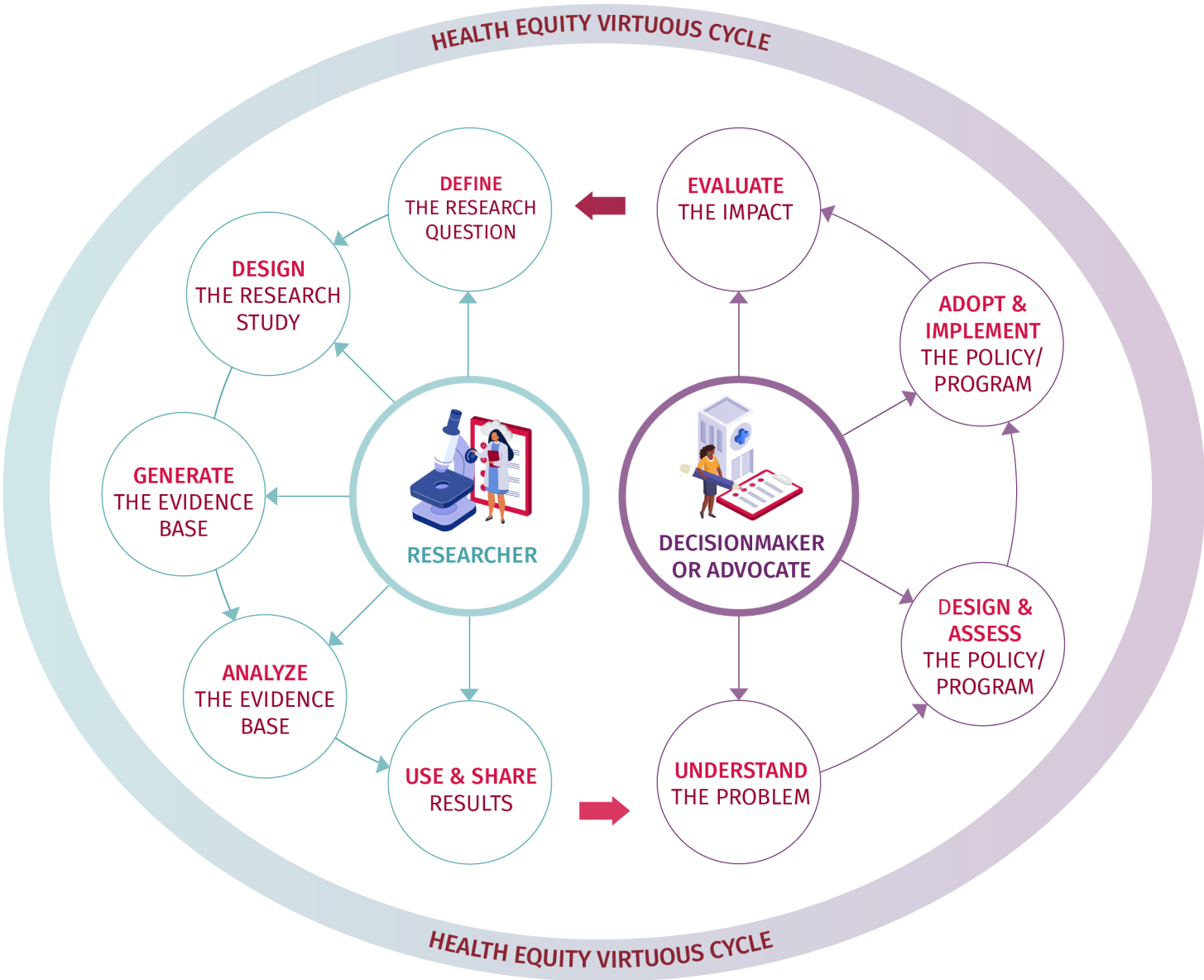
This tool is designed to support people in recognizing these decision points and in *choosing health equity* – whatever and whenever their role may be in this cycle. By posing concrete questions to consider, and providing recommendations and resources for stakeholders to apply, we hope to encourage and support them in building a **Health Equity Virtuous Cycle** that continuously reinforces strategies to identify the drivers of inequities and develop solutions to dismantle them.

The research, policy, and advocacy communities cannot continue to engage in business as usual and expect different results. This Choosing Health Equity tool aims to disrupt standard processes in order to achieve a healthier, equitable, and just society.

HEALTH EQUITY

CHOOSING HEALTH EQUITY:
DECISION POINTS IN RESEARCH AND POLICY

HEALTH EQUITY VIRTUOUS CYCLE

DEFINE THE RESEARCH QUESTION

DESIGN THE RESEARCH STUDY

EVALUATE THE IMPACT

ADOPT & IMPLEMENT THE POLICY/ PROGRAM

GENERATE THE EVIDENCE BASE

RESEARCHER

DECISIONMAKER OR ADVOCATE

DESIGN & ASSESS THE POLICY/ PROGRAM

ANALYZE THE EVIDENCE BASE

USE & SHARE RESULTS

UNDERSTAND THE PROBLEM

HEALTH EQUITY VIRTUOUS CYCLE

HEALTH EQUITY

1. **DEFINE THE RESEARCH QUESTION**

   a. Does this topic have a disparate impact on a priority population group (i.e., communities made vulnerable by structural inequities)?

   b. Are affected patients, people, and communities included in the process of identifying the topic and defining the research question?

   c. Does the research question address the drivers of – or identify solutions to – racial, ethnic, gender, or other inequities?

2. **DESIGN THE RESEARCH STUDY**

   a. Are the affected people and communities included in the design of the study and compensated for their time and expertise?

   b. Does the study design plan for and resource sufficient diversity in participants to enable results to be disaggregated by race and ethnicity, including relevant subgroups (i.e., are you oversampling)?

   c. Does the study design account for and mitigate barriers to participation from diverse and historically underrepresented communities?

   d. Does the study design account for structural and systemic barriers, such as differences in community-level factors that might affect the results for particular groups?

3. **GENERATE THE EVIDENCE BASE**

   a. Is there a standard process to collect disaggregated race, ethnicity, and gender data?

   b. Is there sufficient diverse participation to produce reliable results for disproportionately impacted groups?

   c. Is there a plan or mechanism to address diversity gaps in participation and to prevent dropout?

4. **ANALYZE THE EVIDENCE BASE**

   a. Does the analysis stratify all data, including results, by race, ethnicity, and gender variables (including relevant subgroups)?

   b. Does the analysis include heterogeneity of effect by race, ethnicity, and gender?

   c. Does the analysis consider potential "confounding" factors (e.g., community-level social risk factors that may affect groups differently)?

   d. Are subject communities involved in analyzing and interpreting the results?

5. **USE AND SHARE RESULTS**

   a. Are all results easily accessible to the public in plain language (e.g., on a user-friendly website), including stratified data?

   b. Are subject communities involved in designing and implementing the dissemination plan of the results (e.g., via focus groups, meetings, and storytelling)?

   c. Are the health equity policy and practice implications of the learnings identified?

   d. Are there equity-specific suggestions for further research?

HEALTH EQUITY

1. DEFINE THE RESEARCH QUESTION

1a) DOES THIS TOPIC HAVE A DISPARATE IMPACT ON A PRIORITY POPULATION GROUP (I.E., COMMUNITIES MADE VULNERABLE BY STRUCTURAL INEQUITIES)?

Tell Me More: In a world of limited resources, identifying a topic that has a disparate impact on a priority population group ensures that research focuses on people who face the greatest barriers to health and are in most need of effective solutions. Research that advances health equity prioritizes populations that are most affected, yet underrepresented. PCORI's priority population groups include racial and ethnic minorities, older adults, people with low incomes, residents of rural areas, women, children, people with low health literacy or numeracy, people with limited English proficiency, LGBTQ persons, veterans or members of the armed services, and people with special health needs, such as individuals living with a disability, a chronic condition, or a rare disease. Other priority populations include immigrants.

- What & Who We Fund, PCORI, 2017
- Disparities in Health and Health Care: Five Key Questions and Answers, KFF, 2020
- The State of Health Equity Research: Closing Knowledge Gaps to Address Inequities, Academy Health, 2014

1b) ARE AFFECTED PEOPLE AND COMMUNITIES INCLUDED IN THE PROCESS OF IDENTIFYING THE TOPIC AND DEFINING THE RESEARCH QUESTION?

Tell Me More: People and communities are the experts on what their needs are and the barriers they face. Obtaining their input acknowledges this often-overlooked reality and enables more relevant and usable results. Research that reflects community-defined priorities – instead of being shaped by the perceptions, priorities, and internal biases of research teams or institutions – is most likely to have a positive real-world impact. Researchers should employ a community-based participatory research framework to engage with the affected populations to understand the issues, strengths, and solutions from their perspective, resulting in a stronger study.

- The PCORI Approach to Patient-Centered Outcomes Research, PCORI, n.d.
- AHRQ Activities Using Community-Based Participatory Research to Address Health Care Disparities, AHRQ, 2020
- A Short Guide to Community Based Participatory Action Research, Advancement Project California, 2011

1c) **DOES THE RESEARCH QUESTION ADDRESS THE DRIVERS OF – OR IDENTIFY SOLUTIONS TO – RACIAL, ETHNIC, GENDER, AND OTHER INEQUITIES?**

Tell Me More: A person and a community's health is heavily influenced by the distribution of health risks and health resources, which have been determined by generations of racist and sexist policies and structures. Health care systems and institutions continue to produce disparate outcomes based on race/ethnicity and gender, regardless of the intentions of the people who work within them, because these underlying drivers often go unseen or ignored. Research that contributes to uncovering and understanding the drivers of these inequities and helps identify solutions to them is needed to solve structural and systemic injustices.

- Recognizing, Addressing Unintended Gender Bias in Patient Care, Emily Paulsen, 2019
- Priorities for Research on Equity and Health: Towards an Equity-Focused Health Research Agenda, Piroska Östlin *et al.*, 2011

2. DESIGN THE RESEARCH STUDY

2a) ARE THE AFFECTED PEOPLE AND COMMUNITIES INCLUDED IN THE DESIGN OF THE STUDY AND COMPENSATED FOR THEIR TIME AND EXPERTISE?

Tell Me More: Because people and communities are the experts on what their needs are and the barriers they face, we must include them in designing the study to ensure that research is relevant to their needs, and to enhance the effectiveness and success of the study. They are uniquely positioned to identify obstacles and opportunities, and add tremendous value to the quality of research. In addition to reimbursing these partners' expenses (such as transportation, parking, lodging, meals, and childcare) they must be paid for their time and expertise in recognition of their unique and valuable contributions.

- The PCORI Approach to Patient-Centered Outcomes Research, PCORI, n.d.
- Paying Research Participants: Ethical Guidance for IRBs and Investigators, Harvard Catalyst, 2018
- Compensation for Participation in Research, University of Oregon, n.d.

2b) DOES THE STUDY DESIGN PLAN FOR AND RESOURCE SUFFICIENT DIVERSITY IN PARTICIPANTS TO ENABLE RESULTS TO BE DISAGGREGATED BY RACE AND ETHNICITY, INCLUDING RELEVANT SUBGROUPS (I.E., ARE YOU OVERSAMPLING)?

Tell Me More: Unfortunately, our current health and health care evidence base is not representative of our population. The bulk of research has been conducted with adult white male subjects. While we have made much progress toward the diversification of research participants, much more is needed, particularly among communities of color. Diverse research participation ensures that all communities equitably accrue the benefits of research and medical advancements. Racial, ethnic, and gender inequities can only be eliminated when high-quality data is available to identify them, craft solutions, and monitor progress. Disaggregating by subgroup is critical because the common demographic groups used in the United States aggregate many distinct communities with widely different experiences with health and health care, structural inequities, and the social influencers of health. For example, data that combines all Hispanic or Asian American and Pacific Islanders often mask deep inequities between subgroups. In designing the study, researchers should consider how racial and ethnic groups self-identify and budget for the additional costs associated with recruiting diverse subjects and capturing and disaggregating high-quality data. They should also factor in the investments in time and resources needed to build authentic partnerships with community leaders to foster trust and facilitate culturally respectful outreach.

- Counting a Diverse Nation: Disaggregating Data on Race and ethnicity to Advance a Culture of Health, PolicyLink, 2018
- How data disaggregation matters for Asian Americans and Pacific Islanders Christian Edlagan *et al.*, 2016
- Getting Data Right — and Righteous to Improve Hispanic or Latino Health, Alfonso Rodríguez-Lainz *et al.*, 2016

2c) DOES THE STUDY DESIGN ACCOUNT FOR AND MITIGATE BARRIERS TO PARTICIPATION FROM DIVERSE AND HISTORICALLY UNDERREPRESENTED COMMUNITIES?

Tell Me More: Individuals and communities experience numerous barriers to research participation. These include, but are not limited to, lack of transportation, inability to take time off work or childcare responsibilities, limited English proficiency, lack of access to technology, and other underlying resource inequities. Additionally, institutional racism and misogyny drive well-founded mistrust in the medical establishment and fear of discrimination and mistreatment. Study design should proactively identify these and other barriers, and design processes and structures to address them, such as providing travel support, offering childcare, employing staff who speak participants' native languages, and investing in community partnerships.

- Diversity in Research Participation: Why It's Important, University of California San Francisco, n.d.
- A Systematic Review of Barriers and Facilitators to Minority Research Participation Among African Americans, Latinos, Asian Americans, and Pacific Islanders, Sheba George, 2014
- Recruitment and Retention Strategies for Minority or Poor Clinical Research Participants: Lessons from the Healthy Aging in Neighborhoods of Diversity Across the Life Span Study, Ngozi Ejiogu *et al.*, 2011

2d) DOES THE STUDY DESIGN ACCOUNT FOR STRUCTURAL AND SYSTEMIC BARRIERS, SUCH AS DIFFERENCES IN COMMUNITY-LEVEL FACTORS THAT MIGHT AFFECT THE RESULTS FOR PARTICULAR GROUPS?

Tell Me More: Socioeconomically determined factors that can affect study results are often overlooked despite their powerful effect on health and health care outcomes. Examples include the built environment and specific environmental health risks, quality of housing, experiences with violence, and under-resourcing of institutions such as schools and health care facilities. Designing studies in ways that acknowledge and seek to address these factors will help ensure that results accurately reflect the specific issue being examined.

- Confronting Structural Racism in Research and Policy Analysis, Urban Institute, 2019
- Racism and Health: Evidence and Needed Research, David R. Williams *et al.*, 2019

3. GENERATE THE EVIDENCE BASE

3a) IS THERE A STANDARD PROCESS TO COLLECT DISAGGREGATED RACE, ETHNICITY, AND GENDER DATA?

Tell Me More: Capturing data on race, ethnicity, and gender in consistent ways, and at sufficient levels of granularity, is critical to identifying disparities in outcomes. Researchers should be gathering and coding data in a standardized manner, and with the necessary granularity to facilitate health equity analyses (e.g., disaggregating Asian American participants into more specific groups like Chinese women, Korean men, Vietnamese nonbinary individuals). To improve demographic data collection, researchers should determine appropriate and feasible scope, engage with community members, and develop surveys in-language to allow participants to self-identify their race, ethnicity, and gender.

- Counting a Diverse Nation: Disaggregating Data on Race and Ethnicity to Advance a Culture of Health, PolicyLink, 2018
- Race Data Disaggregation: What Does It Mean? Why Does It Matter?, Nicole MartinRogers, 2018
- Health Equity and Race and Ethnicity Data, Colorado Trust, 2013

3b) IS THERE SUFFICIENT DIVERSE PARTICIPATION TO PRODUCE RELIABLE RESULTS FOR DISPROPORTIONATELY IMPACTED GROUPS?

Tell Me More: Diverse participation ensures that researchers will be able to generalize study results to disproportionately impacted groups. Diverse participation is critical to ensuring that underserved populations will benefit from the health advancements and policy solutions that result from research.

- Importance of Diversity in Clinical Research, ADAPTABLE Study, 2018
- Minorities in Clinical Trials Fact Sheet, U.S. Food & Drug Administration, 2019
- Top 5 Reasons Why Diversity Is Important in Research, University of Maryland, n.d.

HEALTH EQUITY

3c) IS THERE A PLAN OR MECHANISM TO ADDRESS DIVERSITY GAPS IN PARTICIPATION AND TO PREVENT DROPOUT?

Tell Me More: Communities made vulnerable by structural inequities are more likely to face barriers to participation in research. These may include, but are not limited to, lack of transportation, inability to take time off work or childcare responsibilities, limited English proficiency, lack of access to technology, and other underlying resource inequities. Lack of information sharing between researchers and participants regarding the research progress also affects participant retention. Understanding these barriers allows researchers to create a plan or mechanism to support robust participation from priority populations and to prevent dropout. Some examples of efforts to support the ongoing participation of subjects facing structural challenges include: providing robust and relevant participant incentives; well-resourced partnerships with trusted, culturally centered, community-level entities; tailored participant education/appreciation events; flexible policies and support for workers and caregivers; and transparent communication about the goals and progress of the research.

- Overcoming the Barriers to Recruitment of Underrepresented Minorities, Stephanie Lynn Williams, 2018
- Retaining Participants in Outpatient and Community-Based Health Studies: Researchers and Participants in Their Own Words, Donna H. Odierna *et al.*, 2014
- A Systematic Review of Barriers and Facilitators to Minority Research Participation Among African Americans, Latinos, Asian Americans, and Pacific Islanders, Sheba George, 2014

4. ANALYZE THE EVIDENCE BASE

4a) DOES THE ANALYSIS STRATIFY ALL DATA, INCLUDING RESULTS, BY RACE, ETHNICITY, AND GENDER VARIABLES (INCLUDING RELEVANT SUBGROUPS)?

Tell Me More: Collecting disaggregated data is merely the first step in ensuring that research advances health equity. Results must be stratified to enable researchers and other health and health care stakeholders to identify and address inequities in outcomes by race, ethnicity, and gender. Consistent data stratification allows for comparison across multiple entities (e.g., academic institutions, federal and state agencies, research organizations). Such data can be displayed in a dashboard or visualized in other ways to make it easy to review and digest.

- Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement, AHRQ, 2018
- A Framework for Stratifying Race, Ethnicity, and Language data, Health Research & Educational Trust, 2014

HEALTH EQUITY

4b) DOES THE ANALYSIS INCLUDE HETEROGENEITY OF EFFECT BY RACE, ETHNICITY, AND GENDER?

Tell Me More: To advance health equity and be truly patient-centered, research must include a robust analysis of quantitative and qualitative heterogeneity of treatment effects (HTE) by race, ethnicity, gender, and other relevant subgroups. It is the only way to determine groups who may benefit the most, as well as those who may be harmed. Researchers should always complement conclusions related to an "average" participant with transparent HTE results because, in some cases, the effect of the intervention may vary considerably based on an individual or subgroup's characteristics in ways that must be understood to reduce health inequities. Examples of these variances that have concrete negative effects on particular groups include the reduced effect of albuterol on Black and Puerto Rican asthma patients and the increased toxicity of some heart medicine on Asian Americans.

- Estimation and Reporting of Heterogeneity of Treatment Effects, Ravi Varadhan and John D Seeger, 2013
- The Racial Heterogeneity Project: Implications for Educational Research, Practice, and Policy, ACT, 2017
- Genomic Analysis Reveals Why Asthma Inhalers Fail Minority Children, Nicholas Weiler, 2018
- Atherosclerotic Cardiovascular Disease in South Asians in the United States: Epidemiology, Risk Factors, and Treatments: A Scientific Statement From the American Heart Association, Annabelle Santos Volgman *et al.,* 2018

4c) DOES THE ANALYSIS CONSIDER POTENTIAL "CONFOUNDING" FACTORS (E.G., COMMUNITY-LEVEL SOCIAL RISK FACTORS THAT MAY AFFECT GROUPS DIFFERENTLY)?

Tell Me More: When analyzing data, it is important to consider the broader social and economic contexts that shape people's lives and may impact the results. Research analysis must account for the intersectional cultural, socioeconomic, and political factors, as well as structural racism.

- Socioeconomic Environment, Collaborative on Health and the Environment, 2016
- Racism and Health, Robert Wood Johnson Foundation, n.d.
- Social Determinants of Health, World Health Organization, 2010

4d) ARE SUBJECT COMMUNITIES INVOLVED IN ANALYZING AND INTERPRETING THE RESULTS?

Tell Me More: Involving subject communities in analyzing the results ensures that research conclusions are substantiated by the study participants' experiences, rather than being influenced by the perceptions, priorities, and internal biases of research teams or institutions. These individuals provide unique insights on findings, potential confounding factors, and/or unintended consequences that may not have been the focus of researchers, but dramatically affect people's lives. Researchers should employ a community-based participatory research framework to engage with the affected population as active and equal participants to understand study results from the community's perspective.

- Communicating Results of Community-Based Participatory Research, Consuelo H. Wilkins, 2011
- Community-Based Participatory Research: A Strategy for Building Healthy Communities and Promoting Health through Policy Change, Policy Link, 2012

5. USE AND SHARE RESULTS

5a) **ARE ALL RESULTS EASILY ACCESSIBLE TO THE PUBLIC IN PLAIN LANGUAGE (E.G., ON A USER-FRIENDLY WEBSITE), INCLUDING STRATIFIED DATA?**

Tell Me More: *We must ensure that results are stratified by race, ethnicity, gender, and other variables, and easily available in plain language to the broad public. This enhances the effectiveness and speed at which important new information can be applied to improved health care practices, programs, and policies that reduce inequities. It can also increase public confidence in research efforts.* Researchers should communicate study results in language that is simple and easily understood by the general public and avoid scientific jargon. In addition, the public should have unrestricted access to de-identified research results. Results should be displayed on websites that are easy to navigate by populations that have limited technology proficiency.

- 3 Ways to Make Research More Accessible to the Public , Anna Ehler, 2017
- Making research more accessible to inform better policy decisions, Erika Malich, 2017

5b) **ARE SUBJECT COMMUNITIES INVOLVED IN DESIGNING AND IMPLEMENTING THE DISSEMINATION PLAN OF THE RESULTS (E.G., VIA FOCUS GROUPS, MEETINGS, AND STORYTELLING)?**

Tell Me More: *Subject communities play a critical role in advising how to effectively frame and disseminate research results in ways that resonate with the public's priorities and values – especially the people and communities most affected by the inequities the research can address.* Patients and community leaders can identify audiences that could most benefit from the research, and can serve as trusted messengers to connect with these stakeholders. Their ability to leverage personal stories and frame research results in ways that are relevant, evoke emotion, and demonstrate values enhances dissemination and information processing.

- Getting the Word Out: New Approaches for Disseminating Public Health Science, Ross C. Brownson *et al.*, 2018
- Communication and Dissemination Strategies to Facilitate the Use of Health-Related Evidence, AHRQ, 2012

HEALTH EQUITY

5c)   ARE THE HEALTH EQUITY POLICY AND PRACTICE IMPLICATIONS OF THE LEARNINGS IDENTIFIED?

Tell Me More: ***The goal of patient-centered research should be to generate reliable information that can be applied to maximizing health outcomes for everyone by improving health care policies and practices – especially for those with the greatest barriers to good health.*** Researchers should actively work with experts, including from the most affected communities, to identify policy and practice recommendations based on the results, to make it easier for decisionmakers to develop more effective, carefully tailored solutions that serve those most in need.

- Research on health equity in the SDG era: the urgent need for greater focus on implementation, Kumanan Rasanathan *et al.*, 2016
- How Research Can and Should Inform Public Policy, Claire Pomeroy *et al.*, 2015.

5d) ARE THERE EQUITY-SPECIFIC SUGGESTIONS FOR FURTHER RESEARCH?

Tell Me More: ***Presenting limitations and unresolved questions based on the study results, in the context of current research and literature, is an opportunity to surface continuing gaps in the evidence base that must be addressed. Highlighting these evidence gaps, particularly in terms of racial, ethnic, gender, and other inequities, is critically important to directing interest and resources for future research.*** As researchers reflect on study limitations and follow-up research questions, they should prioritize closing knowledge gaps about underserved – and understudied – populations.

- Limited by our Limitations, Paula T. Ross and Nikki L. Bibler Zaidi, 2019
- The State of Health Equity Research: Closing Knowledge Gaps to Address Inequities, American Association of Medical Colleges and AcademyHealth, 2014

Check out the Choosing Health Equity Choice Points Interactive Toolkit at nationalpartnership.org/ChoosingHealthEquity

HEALTH EQUITY

About the Authors

This resource was authored by

Erin Mackay, Managing Director for Health Justice
Dani Gillespie, Health Justice Policy Associate
Sinsi Hernández-Cancio, Vice President for Health Justice

The following people also contributed:

- Sarah Coombs, Director for Health System Transformation
- Caroline Le, Health Justice Intern
- Jorge Morales, Independent Editor
- Nichole Edralin, Designer

For more information, nationalpartnership.org/ChoosingHealthEquity

About the National Partnership

The National Partnership for Women & Families is a nonprofit, nonpartisan advocacy group dedicated to achieving equity for all women. We work to create the conditions that will improve the lives of women and their families by focusing on achieving workplace and economic equity, and advancing health justice by ensuring access to high-quality, affordable, and equitable care, especially for reproductive and maternal health. We are committed to combatting white supremacy and promoting racial equity. We understand that this requires us to abandon race-neutral approaches and center the intersectional experiences of women of color to achieve our mission.

HEALTH EQUITY