

Analysis of NINDS Health Disparities and Health Equity Research Portfolio From 2016 – 2020: Results and a Process for Transparency, Accuracy, and Reliability  
Supplemental Material: Qualitative Coding Schematic and Operational Definitions

1. Disease Area(s), select all (as categorized by RCDC disease area)

- Alzheimer's disease/Alzheimer's disease related dementias (including frontotemporal dementia, Lewy body dementias, and vascular contributions to cognitive impairment and dementia)
- Autism spectrum disorders
- Cerebral palsy
- CNS/PNS neoplasms
- Down syndrome
- Epilepsy
- Essential tremor
- Hydrocephalus
- Multiple sclerosis
- Neuro HIV/AIDS
- Pain (including chronic, migraine/headache, and neuropathic pain)
- Parkinson's disease
- Peripheral neuropathies
- Rare diseases
- Sickle cell disease
- Sleep disorders
- Spinal cord injury
- Stroke
- Traumatic Brain Injury
- Amyotrophic lateral sclerosis (ALS) and other neuromuscular diseases

2. Population(s) Included, select all

- Aging: >65 years of age
- Females
- Immigrants: First generation and/or undocumented status
- Individuals with disabilities: includes physical and intellectual/cognitive disabilities
- Individuals with marginalized health status: e.g., drug users, HIV+, people with serious mental illness
- Institutionalized populations: e.g., persons in criminal justice settings, psychiatric in-patient settings
- Limited education completed: less than high school
- Low socioeconomic status: <\$25,000 annual income
- Non-English speaking or English as a second language
- Pediatric: <18 years of age
- Race and ethnic minorities
- Religious minorities: non-Christian
- Rural population: <50,000 persons per area/cluster

- Sexual or gender minorities: lesbian, gay, bisexual, transgender, queer, intersex, gender non-conforming, etc.
- Other: any other economically or socially disadvantaged, stigmatized, or marginalized population

3. Minority Racial or Ethnic Classification, select all:

- Black or African American (non-Hispanic)
- Hispanic or Latinx
- American Indian or Alaska Native
- Asian American
- Native Hawaiian or Other Pacific Islander
- Other (Specify)

4. Health Equity Determinant(s) Addressed, select all:

- Behavioral: Behavioral determinants consist of actions taken (or not taken) by an individual which can affect their health or mortality. Also called health/lifestyle behaviors, these can include diet, physical activity level, smoking status, alcohol and other drug use, coping strategies, sleep patterns, etc.
- Biological: Biological determinants include factors of differential biological vulnerability, genetics, and epigenetics. Biological and genetic factors can affect specific populations more than others. Examples of biological and genetic determinants can include age, sex (e.g., sex hormones), health status, stress-related biological responses, inherited conditions (such as sickle cell anemia), carrying risk genes, and family medical history.
- Health Care System: Health Care System determinants include access to care, quality of care (including culturally appropriate care), health literacy, health coverage, provider availability, and provider cultural competency. The design of the health care system plays a major role in health outcomes and well-being of individuals.
- Physical/Built Environment: Physical/Built Environment determinants often affect large groups that share common living or working spaces, and include the natural environment or weather, pollution, exposure to toxic substances and other physical hazards, physical barriers, and architectural/other design elements of physical spaces. Built environment factors include the design of buildings, sidewalks, bike lanes, worksites, schools, recreational settings, and housing and community settings.
- Sociocultural: Sociocultural determinants reflect the social and cultural factors on the environment in which people are born, live, play, work, and age. Examples of these determinants are socioeconomic status (SES), education level, language, availability of resources to meet daily needs (such as living wages, educational and job opportunities, and healthful foods), exposures to crime and violence, discrimination, stigma, social hierarchy, and social integration.

5. Type(s) of Research, select all:

- Behavioral: Basic and non-interventional clinical research on how behaviors (especially lifestyle behaviors) are related to disparate health outcomes. NOTE: Basic Experimental Studies with Humans (BESH) is the current NIH terminology for basic behavioral research.

- Mechanistic: Studies are focused on understanding differential biological/genetic factors or causes of health disparities. These studies may incorporate differential molecular and/or genetic changes linked to disparate health outcomes into model systems. Additionally, basic studies may attempt to model social determinants of health (e.g., recapitulate social hierarchies, social stressors) in order to understand the biological consequences of those determinants.
- Screening/Diagnostics: Designing and refining approaches to detect at-risk populations as well as specific disorders and conditions in individuals. Diagnostic research refers to the practice of looking for better ways to identify a particular disorder or condition.
- Prevention: Developing and testing primary and or secondary prevention approaches to reduce disease risk, severity, or progression.
- Interventional: A type of clinical study, often a clinical trial, in which participants are assigned a priori to groups that receive one or more interventions/treatments so that researchers can evaluate the effects of the intervention on health outcomes or proximal measures.
- Interventional/Dissemination & Implementation (D&I): D&I is an integrated concept that links research and practice to accelerate the development, delivery, and scale up of proven health interventions including evidence-based therapeutic, preventative, and diagnostic/screening approaches. Implementation research involves the creation and application of knowledge to improve the implementation (e.g., scale-up) and delivery of evidence-based health interventions, policies, programs, and practices.
- Technology Development: Focused on refining or creating novel technologies for the purpose of improving or understanding health outcomes of individuals. Relevant projects often include mobile and/or telehealth applications. Technology-based interventions and supports are also relevant.
- Observational/Epidemiological: In these studies, investigators are not acting/intervening upon study participants, but instead are observing natural relationships between health factors and outcomes, often with the goal of identifying risk and protective factors. Studies often take place in clinical settings as well as community and other real-world settings.
- Outcomes Research: "Outcomes Research" is a type of post-regulatory (e.g., Phase 4 or later stage) research that seeks to understand the end results of particular health care practices and interventions. Participants receive diagnostic, therapeutic, or other types of evidence-based interventions in real-world settings (already in practice/past regulatory approval stages), but the investigator does not assign participants to a specific interventions/treatment. End measures often focus on short, medium, and or long-term treatment effects that people experience, such as change in the ability to function and quality of life measures.

6. Phase of Research, select one (definitions are based on the NIH/NCATS Translational Science Spectrum, <https://ncats.nih.gov/translation/spectrum>)

- T0 Research/Basic Research: Basic research involves scientific exploration that can reveal fundamental mechanisms of biology, disease or behavior. This typically includes cell and animal studies, and can also include basic behavioral research in humans (non-interventional; non-epidemiological).
- T1 Research/Preclinical Research: Preclinical research involves translation of basic research to the initial development of biomedical interventions, including proof of concept studies, and focus on new methods of diagnosis, treatment, and prevention in highly-controlled settings, not

in humans. During this stage, scientists develop model interventions to further understand the basis of a disease or disorder and find ways to treat it. Testing is carried out using cell or animal models of disease; samples of human or animal tissues; or computer-assisted simulations of drug, device or diagnostic interactions within living systems.

- T2 Research/Clinical Research: Clinical research involves translation to patients, typically including Phase 1, 2 and 3 clinical trials, and controlled studies leading to clinical application and evidence-based guidelines. More broadly, clinical research includes studies to better understand a disease in humans and relate this knowledge to findings in cell or animal models; testing and refinement of new technologies in people; testing of interventions for safety and effectiveness in those with or without disease; behavioral and observational studies; and outcomes and health services research.
- T3 Research/Clinical Implementation Research: Clinical implementation research involves translation to practice, including comparative effectiveness research, post-marketing studies, dissemination & implementation research, and Phase 4 clinical trials. The clinical implementation stage of translation involves the adoption of interventions that have been demonstrated to be useful in a research environment into routine clinical care for the general population. Implementation research may also help identify new clinical questions and gaps in care.
- T4 Research/Public Health Research: Public health research involves translation to communities, including population level outcomes research, monitoring of morbidity, mortality, benefits, and risks, and impacts of policy and change. Researchers study health outcomes at the population level to determine the effects of diseases and efforts to prevent, diagnose and treat them, as well as results of health policy changes. Findings help guide scientists working to assess the effects of current interventions and to develop new ones.

7. Type of Health Equity Intervention(s), select all:

- Case Management: interventions where individual case managers respond to the complexity of navigating the healthcare system by assessing, planning, and facilitating access to health and social services; research participants are delivered an intervention and are monitored on a case-by-case basis with the assistance of a health care provider
- Community Engagement: interventions that link the strengths of the community-setting with health care systems, such as utilization of Community Health Workers & application of Community Based Participatory Research (CBPR)
- Cultural Modification: interventions designed with the needs of specific patient populations in mind (often with patient-level input) and are therefore tailored to a defined population; researchers show cultural competency
- Integrated Health Care: team care approaches, which typically include multi-practitioner involvement in providing/coordinating care and medical decision-making
- Provider Education: interventions to increase provider knowledge, beliefs, and cultural competency regarding a targeted population; interventions seeking to change the way health care providers interact with patients (e.g., bias training); could also include researcher education/cultural competency training

- Patient Education: intervention focuses on improving the knowledge, attitudes, or beliefs of the research participants through an educational intervention; includes interventions focused on individual/patient behavior change
- Policy Interventions: assessing the effects of broad healthcare policy changes, such as assessing different models of care and payment (pay-for-performance, accountable care, etc.) or changes in health or health practice stemming from national health policy changes
- Technological interventions to improve health care access or quality: use of technology such as tele-health to implement intervention
- Enhancing access and/or capacity to deliver service: interventions that can be delivered in home and community settings as well as primary care (vs. specialists), improving cost-efficiency & ease of intervention delivery, health-systems level organizational changes
- Public Communication/Dissemination: E.g., social/public health campaign at community or broader levels; community-targeted communication, education, and dissemination strategies about risk factors, healthy behaviors, health/medical information
- Other
- No health equity interventions are being used

8. Type of Community-based Component(s), if applicable. Select all that apply:

- Community Advisory Board
- Neighborhood Clinic
- Community Health Worker
- Naturally occurring groups, including churches, volunteer organizations
- Patient Advocate
- Social media
- Unable to determine

9. Setting of Intervention Delivery

- Clinic
- Community
- Hospital
- Home
- Church or religious institution
- Private practice
- Other human service (e.g., schools, skilled care facilities)
- Unable to determine

10. Are there considerations for ensuring the sustainability of the intervention over time? (Yes/No)

Guidance: Indicate “yes” if either of these concepts is discussed: 1) the researchers indicate that the research study or implementation of the intervention can be continued after external support is terminated, and/or 2) there are structures and processes in place to allow the implemented innovation to be maintained in a health care system or organization over time.