

The State of Health Equity Research: Closing Knowledge Gaps to Address Inequities

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Executive Summary

Despite significant financial support for health equity research*, health and health care disparities persist. To date, no formal analysis of trends and gaps in funded disparities-focused research has been conducted to ensure targeted investments focus on priority populations, outcomes, and building an evidence base for solutions to health and health care inequities.

Health equity researchers, their funders, and members of the communities whose health they seek to improve could benefit from the identification of research gaps so efforts could be allocated to ensure research-identified solutions are generalizable to the diverse populations that suffer from health inequities.

This report presents results of a qualitative analysis of the “Health Services Research Projects in Progress” database centered on disparities-focused health services research (HSR) funded between 2007 and 2011. The report describes the funders and funding recipients of health disparities-focused HSR, gaps in the populations and outcomes studied, and examines five-year trends in the “evolution” of disparities research from documenting inequities, to investigating causal mechanisms, to identifying solutions.

The analysis revealed:

- Certain health outcomes associated with marked disparities are relatively underrepresented in this research portfolio (e.g., oral health, asthma, adherence to treatment, and sexually transmitted diseases).

- Certain populations that suffer disproportionate morbidity and mortality—such as persons with disabilities, the lesbian, gay, bisexual, and transgender community, rural populations, and American Indians/Native Americans—are relatively underrepresented in disparities-focused HSR.
- Over the five-year period studied, there has been an increasing emphasis on solutions-focused health equity research and a decrease in the proportion of studies that aim solely to detect health inequities.

As health equity research increasingly focuses on identifying solutions to reduce or eliminate health care gaps, and as more Americans obtain access to care as insurance coverage expands, there are unique opportunities for funders, policymakers, and other stakeholders to identify and respond to the gaps identified by this research and develop research protocols that address understudied populations and outcomes.

*Throughout this report the terms “health equity research” and “health disparities research” are used interchangeably and refer to any investigation that seeks to detect, understand or reduce/eliminate an inequity in health or health care.

Introduction

Systematic, measurable, and avoidable health and health care inequities persist in the United States.^{1,2} Certain demographic groups including racial and ethnic minorities and the poor continue to experience disproportionate morbidity and mortality. Despite decades of effort and commitment, the existing evidence base for policy- and research-driven solutions remains insufficient.³⁻⁵

In 2012, according to the National Institutes of Health (NIH) Office of Budget, NIH spent more than \$2.7 billion on projects classified as “health disparities research” by the Research, Condition, and Disease Categories system.⁶ Of 235 disease categories, funding for health disparities research ranked 16th.⁶ However, to date no effort has been made to conduct a comprehensive portfolio analysis of health disparities- or health equity-focused research with the goal of understanding whether these targeted investments are addressing key health disparities and all priority populations. Ultimately, understanding the direction of current and future investigations is needed to support the type of solutions-focused research that will enable society to close or narrow health and health care gaps.

Health equity research (HER) can be grouped into three “generations” that are defined by the investigation’s focus on documenting disparities (1st generation), understanding the mechanisms that give rise to disparities (2nd generation), or reducing/eliminating disparities (3rd generation).⁷ While believed to be in its nascent stages, 3rd generation research is crucial to reducing inequities.⁸ Indeed, certain funders of HER such as the Patient-Centered Outcomes Research Institute (PCORI) explicitly state in application materials that only projects that aim “...to reduce or eliminate disparities in health and health care” will be funded.⁹

Solutions to health and health care inequities will necessarily incorporate evidence derived from investigations across the research spectrum. Epigenetics and genomics, comparative effectiveness research, and community-based participatory research (CBPR) will contribute to the evidence base for solutions from each methodology’s unique perspective and insight into the complex, multilevel systems and structures that give rise to disparities in health and health care. Health services research (HSR), with its focus on access, service utilization, and patient outcomes, will undoubtedly contribute concrete actions that health care systems and practitioners can take to move the needle toward equity. Given the Patient Protection and Affordable Care Act’s focus on payment and system redesign and on increasing access to health care,¹⁰ it is increasingly important to assess whether or not health services researchers and the organizations that fund them are focusing on developing solutions for the populations and health outcomes that contribute most to health care disparities in the United States.

Using the National Library of Medicine’s “Health Services Research Projects (HSRProj) in Progress” database,¹¹ this study aims to analyze trends (2007–2011) in funding, HER generation, populations and outcomes studied, and grantee institutions of health disparities-focused HSR in order to identify opportunities for policymakers, health services researchers, funders, and other stakeholders.

Methods

In April 2013, the research team obtained a Microsoft Access file from AcademyHealth containing all HSRProj records funded through 2011. (Complete 2012 data were not available at that time.) HSRProj is a free online database that systematically identifies the most up-to-date projects in the field and contains descriptions of more than 23,000 current health services research projects funded by 147 different organizations, including government and state agencies, foundations, and private organizations. HSRProj is a joint effort of AcademyHealth, the Cecil G. Sheps Center for Health Services Research at the University of North Carolina at Chapel Hill, and the National Library of Medicine, National Institutes of Health, Department of Health and Human Services, which provides funding and support for the database. To be listed in HSRProj, a research project must be in the field of HSR and can be submitted by either the funding organization or the study's principal investigator.

Query Development and Sampling

The HSRProj database query was developed based on the research team's operational definition of HER: "Research aimed at detecting, understanding, or reducing/eliminating differences in health between groups stemming from differences in levels of social advantage/disadvantage." The query included the search terms "disparities" or "disparity" as well as a list of 55 research-team generated identity-related keywords designed to capture populations (e.g., Native Americans, blacks, lesbian, gay, bisexual, and transgender (LGBT), low socioeconomic status groups, etc.) that suffer from health and health care disparities. To provide a comprehensive review of recently funded disparities-focused HSR, all projects with an initial funding date between 2007 and 2011 were searched.

Abstracts retrieved from the initial query search were subsequently subjected to a set of exclusion criteria in order to determine the final sample of disparities-focused HSR projects. Abstracts were excluded from consideration for the project if: (a) health and/or health care disparities were not discussed explicitly or implicitly in the project abstract; (b) the abstract described a meeting or a conference, as such events do not in and of themselves aim to detect, understand, or eliminate health inequities; (c) the abstract was funded via a training grant (i.e., NIH-funded T-mechanism), as these abstracts often did not contain enough detail to allow for deeper coding; or (d) the abstract did not describe HER as defined by the above operational definition.

Coding Process

The research team developed an initial set of a priori codes in order to categorize projects in terms of the population(s) studied, the outcome(s) assessed, and whether the research aimed to detect, understand, or reduce/eliminate disparities.

Before coding began, the team of five coders undertook an iterative training process. This process continued until coders achieved and maintained satisfactory interrater reliability (Kappa statistic > 0.7) for *mutually exclusive codes* (e.g., does the project describe HER?), and percent agreement above 80 percent was achieved for *non-mutually exclusive codes* (e.g., HER generation). Interrater reliability and percent agreement were assessed every three weeks during the coding process to ensure a high level of agreement and initiate retraining, if necessary.

Methods (continued)

The initial codebook included 60 population/identity codes, 93 outcome codes (e.g., disease or health outcomes studied), and three HER generation codes (e.g., detect, understand, reduce/eliminate). Four codes related to the project's hypothesized contributors to the disparity were also included (genes, individual risk behavior, health system factors, and/or social determinants of health). None of these codes were mutually exclusive.

During the coding process, the coding guide was revised to incorporate emerging codes as new populations and outcomes were identified. The final version of the codebook contained 89 population/identity codes and 145 outcome codes.

All coding and analyses were conducted using NVivo 10 software.

Other Analyses

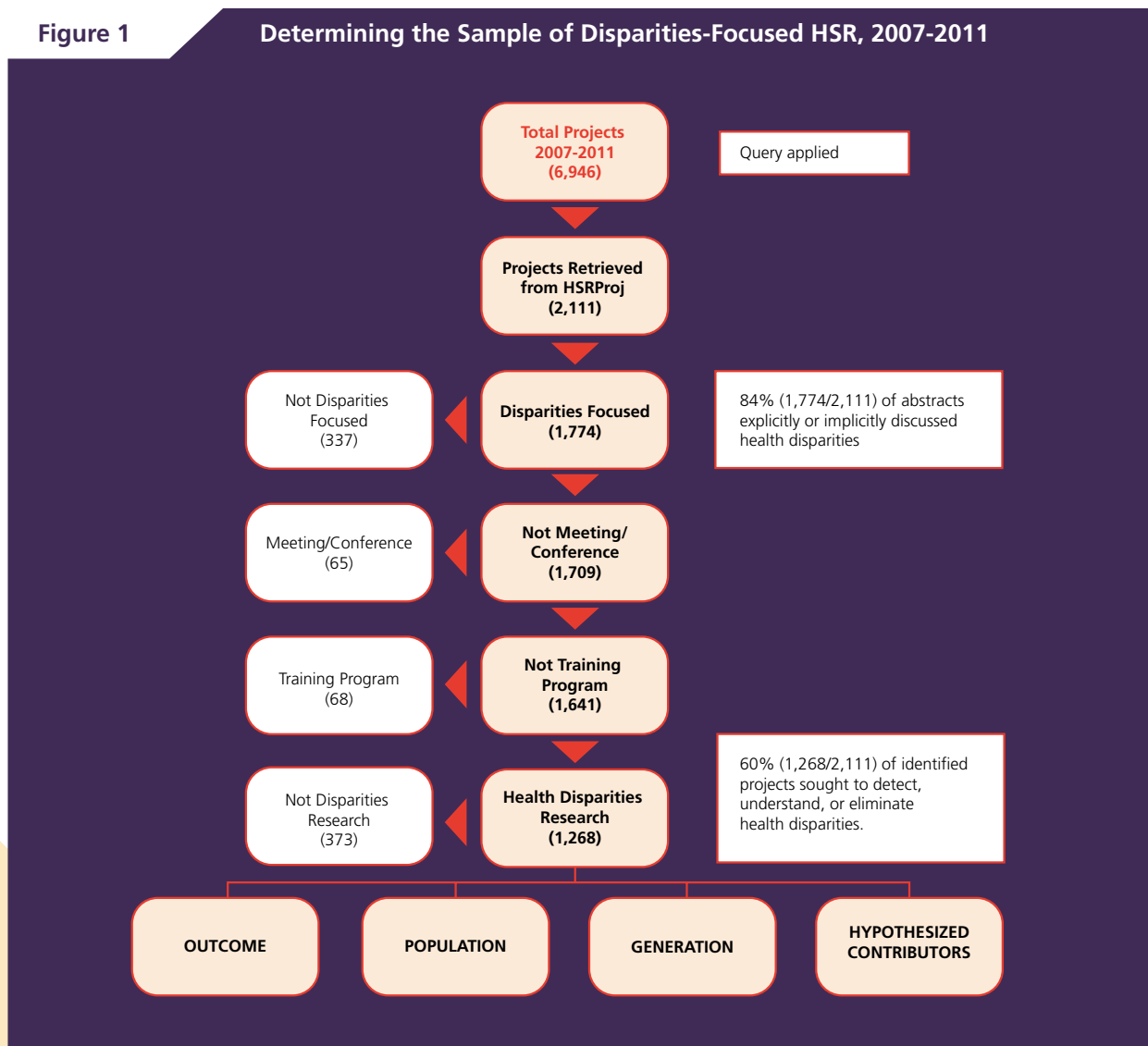
The Carnegie Classification of Institutions of Higher Education system was used to categorize organizations funded to conduct disparities-focused HSR by level of degrees awarded (e.g., bachelor's degrees, doctoral degrees) and the institution's special emphasis/focus, if any. Doctorate-granting universities, those awarding more than 20 research doctorates a year, also were classified by their level of research activity (e.g., very high research activity or high research activity). Other funded organizations received a "special emphasis" designation based upon the high concentration of degrees within a certain field (e.g., special emphasis in medicine/health). Only the institution that directly received funding to conduct the research project was categorized.

The HSRProj database did not contain funding amounts at the time of this analysis. Total project support, in dollars, was collected from a variety of sources. For projects supported by federal agencies (e.g., NIH, Agency for Healthcare Research and Quality, Centers for Disease Control and Prevention, Health Resources and Services Administration), the research team was able to retrieve the funding dollars per project from either the NIH RePORTER database or the Tracking Accountability in Government Grants System. For those projects that received funding from a foundation (e.g., Robert Wood Johnson Foundation, Commonwealth Fund), the funding dollars were gleaned from the foundation's website. The research team also searched performing organizations' websites for funding information that could not be ascertained via the aforementioned methods. Funding information for projects funded by the Veterans Administration (VA) was unavailable.

Results

Figure 1 shows the total number of projects in the final sample of disparities-focused HSR project abstracts. Our initial query retrieved 2,111 (30 percent) of the 6,946 projects in the HSRProj database with an initial start year of 2007–2011. After application of the exclusion criteria, 1,268 abstracts (60 percent of those retrieved by the initial search) described HER based on the definition generated for this project.

Figure 1 Determining the Sample of Disparities-Focused HSR, 2007-2011



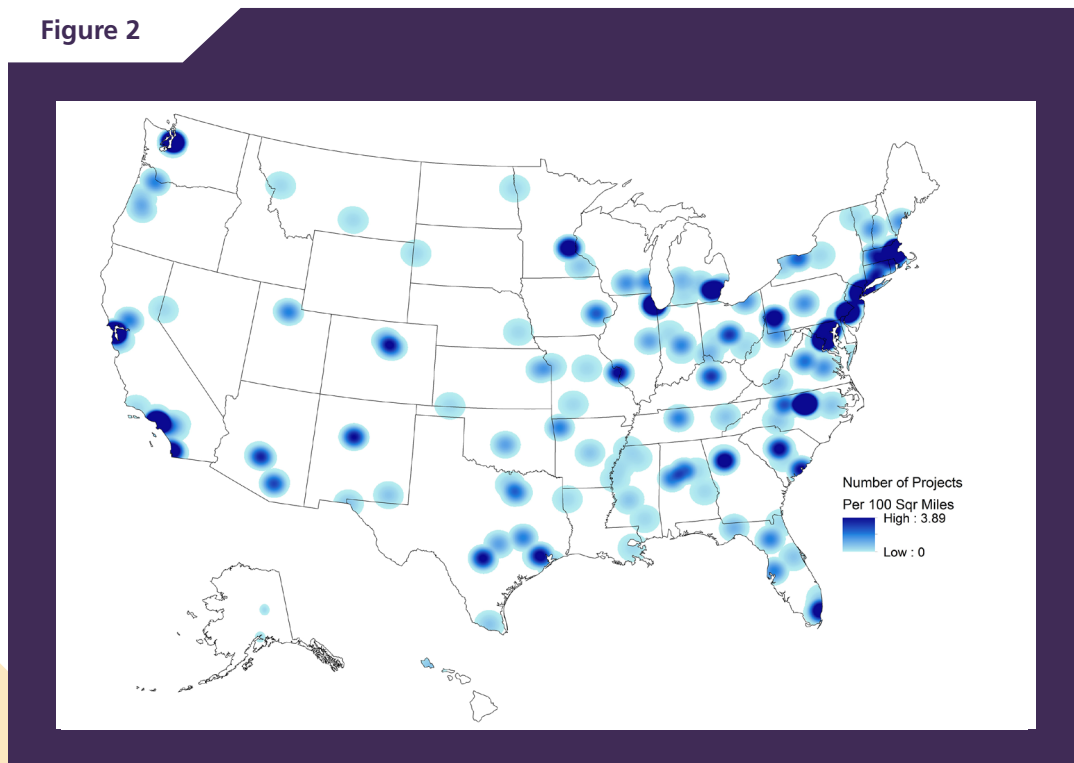
Results (continued)

Consistent with the location of major research universities, **Figure 2** shows a concentration of projects along the eastern and western coasts of the United States.

According to the Carnegie Classification designation of organizations, universities with very high research activity conducted the highest percentage of disparities-focused HSR projects (57 percent; n=726). The specific research setting of the disparities-focused research projects varied: 29 percent (n=371) of identified projects were conducted at schools of medicine, 14 percent (n=181) at teaching hospitals (including VA teaching hospitals), 12 percent (n=149) at schools of public health, and 14 percent (n=181) at organizations outside the academic setting.

Between 2007 and 2011, the National Institutes of Health provided over \$390 million to support health disparities-focused HSR, as defined. When Institutes and other funders were considered individually, the National Institute on Minority Health and Health Disparities contributed the most financial support for disparities-focused HSR and awarded approximately \$82 million to institutions to conduct this research. Other top funders of disparities-focused HSR were the Robert Wood Johnson Foundation (\$72 million), National Cancer Institute (\$54 million), National Institute of Mental Health (\$47 million), and the Agency for Healthcare Research and Quality (\$43 million).

Figure 2



Results (continued)

As shown in **Table 1**, adolescents and children (24 percent), blacks/African Americans (23 percent), and low socioeconomic status groups (23 percent) were the most frequently studied populations in disparities-focused HSR. Other vulnerable populations were relatively less likely to be studied. Fewer research efforts were aimed to detect, understand, or eliminate disparities affecting rural groups (7 percent), LGBT populations (3 percent), American Indians/Native Americans (3 percent), and persons with disabilities (2 percent).

Table 1: Populations Studied in Disparities-Focused Health Services Research Projects (2007-2011), n=1,268

Population Studied*	Percent (#) of Total Projects
Adolescents and Children	24% (299)
Blacks/African Americans	23% (291)
Low Socioeconomic Status Groups	23% (290)
Hispanics/Latinos	18% (233)
Racial/Ethnic Minority, not specified	10% (121)
Rural Populations	7% (92)
Elderly	6% (80)
LGBT Populations	3% (38)
Asian Americans	3% (35)
American Indians / Native Americans	3% (34)
Persons with Disabilities	2% (31)
Veterans	2% (24)
Pacific Islanders/Native Hawaiians	<1% (5)

* Population codes not mutually exclusive

Results (continued)

Outcomes related to health care delivery (a category that included issues of access, patient-provider communication, quality of care, etc.) were most likely to be studied in the portfolio of disparities-focused HSR analyzed here (**Table 2**). Cancer, mental health, and outcomes related to diet, obesity, and physical activity also were well represented in projects funded between 2007 and 2011. Certain conditions for which disparities are prevalent such as asthma, cardiovascular disease, HIV, and sexually transmitted diseases, comprised a much smaller segment of disparities-focused HSR.

Table 2: Health Outcomes Assessed in Disparities-Focused Health Services Research Projects (2007-2011), n=1,268

Health Outcome Assessed*	Percent of Total Projects
Healthcare Delivery	51% (647)
Cancer (All Types)	25% (304)
Diet, Obesity, and Physical Activity	18% (229)
Mental Health	15% (195)
Prevention/Screening	7% (93)
HIV and AIDS	7% (93)
Diabetes	7% (82)
Substance Disorders	6% (75)
Cardiovascular Health	6% (74)
General Health	5% (68)
Adherence to Treatment	4% (54)
Tobacco Use	4% (51)
STDs and Sexual Health	4% (45)
Mortality	3% (40)
Oral Health	3% (40)
Kidney Conditions	2% (22)
Asthma	2% (21)
Developmental Disabilities	1% (13)

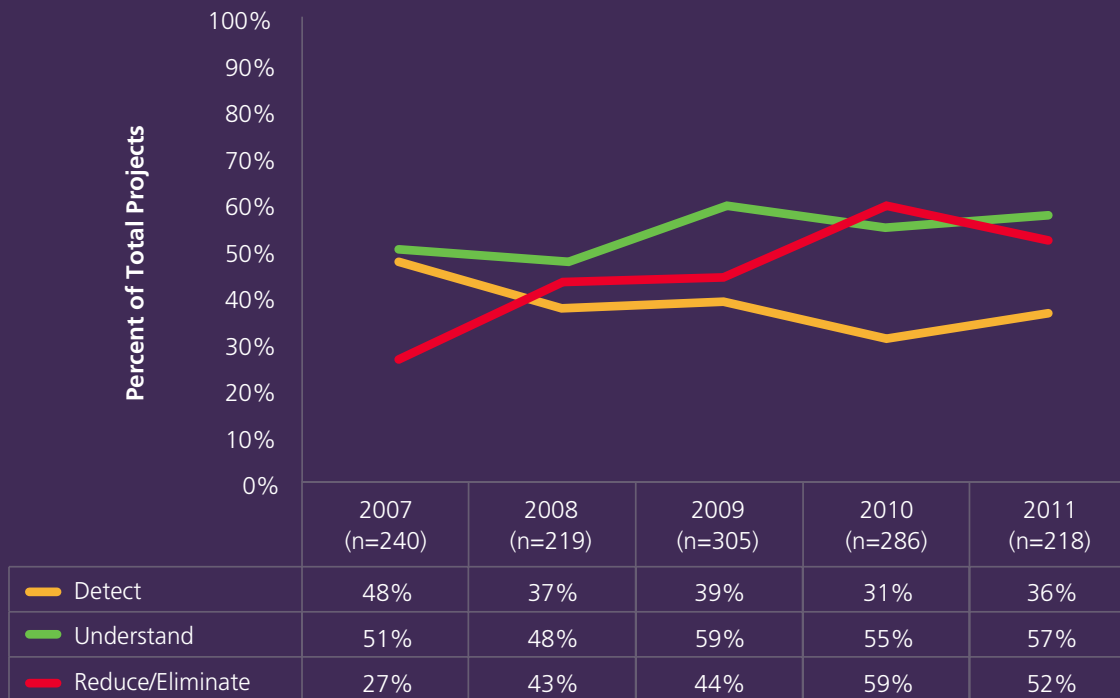
* Outcome codes not mutually exclusive

Results (continued)

As shown in **Figure 3**, between 2007 and 2011, the proportion of disparities-focused HSR that aimed to identify solutions to disparities (3rd generation HER) increased by 93 percent. By comparison, the proportion of studies describing inequities (1st generation HER) fell by 25 percent. Whereas in 2007, less than one-third of disparities-focused HSR projects sought to build an evidence base for solutions to health and health care inequities, by 2011, more than half (52 percent) of disparities-focused HSR aimed to reduce or eliminate a documented inequity.

Figure 3

Health Equity Research "Generation"* of Disparities-Focused Health Services Research (2007-2011) n=1,268



*Generation codes not mutually exclusive

Discussion

The federal government, via policy statements (e.g., Healthy People 2020), funding mechanisms (e.g., NIH-funded Health Disparities Centers of Excellence), and legislation (e.g., the Affordable Care Act) has set the reduction and elimination of health and health care inequities as a major goal.^{10,12-14} Yet despite these efforts, inequities persist. Results of this research can guide both federal and nonfederal funders so resources are allocated to health outcomes and population groups currently underrepresented in disparities-focused HSR and to projects that aim to build the evidence base for solutions to these gaps. By targeting funding efforts in this way, we can hasten the development of an evidence base that is responsive to communities that could benefit most.

As recently as 2007, 3rd generation HER was thought to be in its early stages.⁷ This research documents that the transition from 2nd to 3rd generation disparities research is well underway; more than half of projects funded in 2011 sought to understand or solve disparities while less than one-third of projects aimed to detect inequities (1st generation). However, the projects analyzed here are newly funded pieces of research and present an early view of the communities and conditions for which an evidence base might develop as these projects near completion. Thus, while the transition may be underway, society will not reap the rewards for some time. As the body of 3rd generation HER develops and the funded projects analyzed here bear fruit in the form of publications and evidence-based programs, efforts to reduce disparities will be accelerated if researchers, funders, and policymakers compile and disseminate successful initiatives so they may be implemented—and tested—broadly. Financial support for research that seeks to replicate successful programs and policies in disparate contexts will be

key to identifying, scaling, and spreading initiatives that effectively close or narrow health and health care gaps.

Despite this encouraging trend, not all populations that experience disproportionate morbidity and mortality receive equal attention from health services researchers and their funders. While black and Hispanic Americans as well as groups from lower socioeconomic status backgrounds are well represented in the disparities-focused HSR portfolio, rural, LGBT, American Indians/Native American populations, and persons living with disabilities are underrepresented relative to both the severity of health and health care disparities they experience and their representation within the American population.

The geographic distribution of disparities focused-HSR is suggestive of the need to further evaluate and invest in local capacity to conduct HSR. HER benefits from deep and meaningful community engagement between local institutions, researchers, and residents. Thus, building institutional capacity and inter-institutional research partnerships to conduct disparities-focused HSR in areas currently not receiving funding dollars should be a priority. Furthermore, results of this research could be used to target extant funding streams on specific populations to ensure the evidence base developed by 3rd generation HER can be generalized to all groups adversely affected by health and health care inequities.

Similarly, while it is no surprise that outcomes related to the health system are the most studied by disparities-focused HSR, certain conditions and diseases with marked disparities across priority populations (e.g., asthma, oral health, and cardiovascular disease) were relatively under-investigated. HSR is particularly well suited to study

Discussion (continued)

disparities in many of these conditions. This current research can be used by specific NIH institutes as well as foundations with focused funding areas to develop new grant opportunities or broaden existing ones to target conditions for which the HER evidence base is still in its early stages. Patient advocacy groups also could use this research to work with funders and donors to establish new targeted funding streams.

Despite the comprehensiveness of the current research, there are some limitations.

By definition, the HSRProj database only captures health services research projects. While 3rd generation disparities-focused HSR will contribute one set of solutions to health care inequities, research from across the full spectrum and collaborations between various sectors of society are also necessary if we are to significantly reduce or eliminate health gaps. Thus, this current investigation, while comprehensive in its assessment of HSR, only paints one piece of the picture. Other solutions-focused research occurs at other nodes in the spectrum that are not captured here.

The exclusion of training programs (NIH T-mechanisms, specifically) due to lack of detail may underestimate disparities-focused HSR activity. However, given the relatively small number of excluded training programs (n=68), the findings would not change significantly had we included them. Similarly, our initial search terms were generated via an iterative process in an attempt to maximize sensitivity and minimize false positives. In order to focus the search, the research team chose not to include terms related to methodologies likely employed in HER (e.g., CBPR) or general terms like “access.” It is possible that excluded terms would

have accurately identified additional projects had they been included.

The ranking of top funders of disparities-focused HSR presented here is potentially inaccurate as funding data for VA-funded research were unavailable. However, in terms of the number of projects funded, the VA ranked 9th overall. Thus, it is unlikely that it would have been included in the top five funding agencies (by dollars) discussed above.

Despite these limitations, the descriptive analyses presented here provide a novel and important picture of HER. As HER increasingly focuses on identifying solutions to reduce or eliminate health care gaps, and as more Americans obtain access to care as insurance coverage expands, there are unique opportunities for funders, policymakers, and other stakeholders to identify and respond to the gaps identified here and develop research protocols that address understudied populations and outcomes. Strategic investments in institutions and researchers in areas currently underrepresented in the disparities-focused HSR portfolio may present one option for building capacity to engage with local communities and health care systems to address population health gaps.

Future opportunities for HER include an effort to most appropriately target investments in disparities-focused HSR, particularly to scale and spread lessons learned from 3rd generation HER. Future funding strategies may benefit from stratifying the economic, social, and health-related costs of health inequities by population, outcome, and region. Comparing the current investments outlined in this work to the documented and persistent needs of diverse communities will provide an opportunity to maximize the value of health equity research for all members of our society.

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