November 30, 2022

Brian C. Moyer, PhD
Director
National Center for Health Statistics
Centers for Disease Control and Prevention
Department of Health and Human Services
3311 Toledo Road
Hyattsville, Maryland 20782

Re: Recommendations on Measures of Discrimination for Use in NCHS Surveys

Dear Dr. Moyer:

This letter conveys recommendations to the National Center for Health Statistics (NCHS) from the Board of Scientific Counselors (BSC) on NCHS' efforts to add discrimination measures to its nationally representative surveys. The Board conducted this work in fulfillment of its charge to provide advice and guidance and make recommendations on statistical and epidemiological research and activities.

Until recently, none of the Center's surveys has measured adult respondents' perceptions of recent experience with discrimination. Despite decades of research into the association between health and discrimination, there is not currently a nationally representative data source that permits ongoing evaluation of the association between recent experiences of discrimination and health outcomes for adults of all ages. Research findings indicate that discrimination is an important psychosocial stressor contributing to health disparities with chronic everyday discrimination being a stronger predictor of negative health outcomes than acute experiences of discrimination.

You asked the Board to explore whether incorporating discrimination measures into NCHS surveys could give NCHS and survey data users the ability to quantify and track the prevalence of discrimination and the relationships between discrimination and key health indicators in nationally representative samples. At the February 10, 2022, meeting of the Board, NCHS requested that the Board advise on whether it is feasible and practical to include measures of discrimination on NCHS surveys such as the National Health Interview Survey (NHIS), the National Health and Nutrition Examination Survey (NHANES), and/or the National Survey of Family Growth (NSFG). During the meeting, the Board voted unanimously to approve the creation of a Workgroup to Consider and Assess Measures of Discrimination for Use in NCHS Surveys (WCAMD). Kristen Olson, PhD, volunteered to serve as chair and six additional BSC members participated including the Board chair.

Over the course of spring and summer 2022, the Workgroup convened to study the feasibility, practicality and methodological considerations of adding questions to each of the main nationally representative NCHS surveys. The key guiding questions that the Workgroup researched included:

1) Given the limited space available on the NHIS, NSFG and NHANES, does the Board consider this an achievable goal for NCHS?
2) How best can NHIS, NSFG, and NHANES data collection contribute to future research and/or surveillance efforts related to racism and discrimination?
3) Should NCHS surveys have a focus on discrimination in health care settings or consider experiences of discrimination more generally?
4) Would it be beneficial for NCHS to adopt an intersectional approach to measuring discrimination?
5) Given similarities and differences in the purposes and core content of NHIS, NSFG, and NHANES, should discrimination content (if any) be similar or different across NCHS surveys? If so, how – what are viable options?

You also requested that the BSC advise on the criteria to use when NCHS would decide to select a discrimination measure given research and study findings available in the literature thus far. And also to advise on additional research that would be a valuable contribution to inform NCHS' future decisions on use of questions to measure discrimination.

As part of gathering information to develop its findings, the Workgroup invited researchers with established expertise in this area as well as CDC scientists and other subject matter experts to meet with them. With this additional input, the Workgroup developed a Findings Report on its work that members shared with the full Board during the October 24, 2022 meeting. The overarching finding of the Workgroup is that the inclusion of discrimination measures in NCHS surveys is an achievable goal for the Center. The Workgroup included additional detail such as whether to ask survey respondents specifically about experience with discrimination in health care settings. The Board adopted the Workgroup's finding that, because not all US adults regularly visit health care settings, asking only about discrimination in health care settings is likely to not be applicable to all respondents. Thus, measuring respondents' experiences of discrimination across multiple domains would need to include but not be limited to health care settings, an important facet when designing new items for surveys.

At the October meeting, the Board unanimously approved a motion to submit the findings laid out in the enclosed Findings Report as recommendations to NCHS from the Board as follows:

1. The Board accepts the findings from the report from the NCHS BSC Workgroup to Consider and Assess Measures of Discrimination for Use in NCHS Surveys.
2. The Board recommends that NCHS include measures of discrimination in the NHIS, NHANES, and NSFG, based on question evaluation and testing, amount of time available in each survey, and review of the literature.
3. The Board recommends that NCHS include measures of heightened vigilance in the NHIS, NHANES, and NSFG, based on question evaluation and testing, amount of time available in each survey, and review of the literature.

Thank you for considering the Board's recommendations. The Board strongly encourages NCHS to move forward with implementation of this work taking into account the details outlined in the Findings Report.

The Board is available to answer questions and will continue to support NCHS' efforts to advance innovative approaches for monitoring and evaluating important public health and health policy questions of national interest.

Sincerely,

/s/

John R. Lumpkin, MD, MPH
Chair, Board of Scientific Counselors
National Center for Health Statistics

Enclosure: Findings Report: Considerations and Assessment of Measures of Discrimination for Use in NCHS Surveys, to the BSC, October 24, 2022

Considerations and Assessment of Measures of Discrimination for Use in NCHS Surveys

National Center for Health Statistics (NCHS)

Board of Scientific Counselors (BSC)

NCHS BSC Workgroup to Consider and Assess Measures of Discrimination for Use in NCHS Surveys

Workgroup Findings

October 20, 2022

Executive Secretary/Designated Federal Officer, BSC NCHS
Rebecca Hines, MHS

BSC NCHS WCAMD Workgroup Members
Kristen Olson, PhD, University of Nebraska-Lincoln
Scott Holan, PhD, University of Missouri
Helen Levy, PhD, University of Michigan
Andy Peytchev, PhD, RTI International
C. Matthew Snipp, PhD, Stanford University
David Williams, PhD, MPH, Harvard University

John Lumpkin, MD, MPH, BSC Chair
Blue Cross and Blue Shield of North Carolina Foundation

NCHS Members
Stephen Blumberg, PhD, Director, Division of Health Interview Statistics
Anjani Chandra, PhD, NSFG Team Lead
Denys Lau, PhD, Senior Science Advisor, Division of Health and Nutrition Examination Surveys

NCHS Staff
Jonaki Bose, Senior Advisor, Division of Health Interview Statistics
Cheryl Fryar, MSPH, Health Statistician, Division of Health and Nutrition Examination Surveys
Kristen Miller, PhD, Senior Methodologist, Division of Research and Methodology
Tina Norris, PhD, Data Scientist, Division of Health Interview Statistics
Jennifer Parker, PhD, Director, Division of Research and Methodology
Paul Scanlon, PhD, Survey Methodologist, Division of Research and Methodology
Anjel Vahratian, PhD, MPH, Associate Director for Science, Division of Health Interview Statistics

Invited Subject Matter Experts

- **LCDR Rashid Njai, PhD, MPH,** Minority Health and Health Equity Science Team, CDC
- **Tina Norris, PhD,** Data Scientist, Division of Health Interview Statistics
- **Margaret Hicken, MPH, PhD,** Associate Professor, Survey Research Center and Division of Nephrology, Dept of Internal Medicine, Michigan Medicine; Faculty Associate, Population Studies Center, University of Michigan
- **Tené Lewis, PhD, FABMR, FAHA,** Associate Professor, Department of Epidemiology, Emory University Rollins School of Public Health
- **Gilbert Gee, PhD,** Professor, Department of Community Health Sciences, University of California Los Angeles (UCLA)

Background

Healthy People 2030 states that understanding Social Determinants of Health (SDOH) is a priority area for achieving "health and well-being for all." Examples of SDOH provided by Healthy People 2030 include "racism, discrimination, and violence." Additionally, the Centers for Disease Control and Prevention (CDC) states that "racism—both interpersonal and structural—negatively affects the mental and physical health of millions of people, preventing them from attaining their highest level of health, and consequently, affecting the health of our nation."

Discrimination is one form of racism that acts as an important psychosocial stressor contributing to health disparities across racial and ethnic groups. When experiences of discrimination are chronic, ongoing, or frequent experiences, ruminative or anticipatory stress around experiencing discrimination that has been shown to activate a biological stress response. Meta-analyses and systematic reviews have shown consistent associations between discrimination and the stress-related biomarkers of inflammatory response (Cuevas et al. 2020; Lawrence et al. 2022), and consistent associations between discrimination and a wide range of self-reported physical and mental health outcomes (Paradies 2006; Williams et al. 2019; Williams and Mohammed 2009). Furthermore, there is a dose-response relationship between reporting more experiences with discrimination and health outcomes (Lewis et al. 2011; Michaels et al. 2019; Williams, Lawrence and Davis 2019). Furthermore, chronic everyday discrimination is a stronger predictor of negative health outcomes than acute experiences of discrimination.

NCHS surveys such as the National Health Interview Survey (NHIS), National Survey of Family Growth (NSFG), and National Health and Nutrition Examination Survey (NHANES) do not currently collect information about experiences of discrimination. Incorporating discrimination measures — measures that assess one aspect of racism, namely experiences of interpersonal racial discrimination and other forms of discrimination due to non-dominant social identity or position — into NCHS surveys such as the NHIS, NSFG, and NHANES could give NCHS and survey data users the ability to quantify and track the prevalence of discrimination and the relationships between discrimination and key health indicators in nationally representative samples. Despite decades of research into the association between health and discrimination, there is not currently a nationally representative data source that permits ongoing evaluation of the association between individuals' experiences of discrimination and health outcomes.

Charge to the Workgroup

NCHS posed a number of questions to the Board of Scientific Counselors, which the Workgroup studied and assessed, as follows:

Part A. Feasible and practical.

1) Given the limited space available on the NHIS, NSFG and NHANES, does the BSC consider this an achievable goal for NCHS?
2) If so, what are the most important contributions NCHS can make by including measures of discrimination on the NHIS, NSFG, and/or NHANES?
3) How best can NHIS, NSFG, and NHANES data collection contribute to research and/or surveillance efforts related to racism and discrimination?
4) Should NCHS surveys have a focus on discrimination in health care settings or consider experiences of discrimination more generally?
5) Given similarities and differences in the purposes and core content of NHIS, NSFG, and NHANES, should discrimination content (if any) be similar or different across NCHS surveys?

Part B. Methodological Considerations.

1) Should the surveys measure the perceived reason (attribution) for discrimination? If so, is a one or two stage approach recommended for measuring discrimination on NCHS surveys? A two-stage approach first solicits information about experience with discrimination and then asks questions about the reasons why respondents think such experiences occurred.
2) If attribution is assessed, would it be beneficial to include “mark all that apply” options?
3) Would it be beneficial to adopt an intersectional approach to measuring discrimination? If yes, what would be the best way to accomplish this based on the number and nature of questions/response options recommended?
4) What would be the most appropriate scale to use for a face-to-face interviewer administered survey like the NHIS? Does the recommendation change if self-response is an option, as can be done using computer-assisted self-interviewing (CASI) within NHANES and NSFG?
5) What is the most appropriate reference/recall period for cross-sectional surveys such as NHIS, NHANES, and NSFG?
6) Are there other aspects of the measurement of discrimination that should be taken into consideration when being included on NCHS surveys (e.g., how to best handle comprehension, skipping/don’t know, etc.)?
7) Is additional developmental research needed? For example, would using open-ended question follow-ups and/or cognitive interviewing be beneficial to ascertain how respondents comprehend discrimination/unfair treatment?

The Workgroup posed three additional questions which framed our discussion with the subject matter experts.

1) What concepts are the strongest, most useful, or most consistent predictors of health outcomes?
2) What concepts explain variance above and beyond information traditionally collected in NCHS surveys?
3) Are certain concepts or measures "better" (stronger, more reliable, more likely to be endorsed, easier to be answered) for certain subgroups?

Information Gathering

To inform its work, the Workgroup requested information from CDC officials and researchers and from academic scholars who actively conduct research examining health effects of discrimination. The Workgroup developed questions and invited the experts, listed under "invited subject matter experts" above, in a series of two virtual meetings between April 26, 2022 and July 13, 2022. Each invited expert provided a brief presentation, followed by discussion between the invited experts, BSC and NCHS Workgroup members and NCHS survey representatives. The Workgroup also reviewed past research using alternative measures of discrimination meeting on six occasions to complete the work.

Findings

The main findings are organized by the questions posed by NCHS.

Achievable goal. Yes, the inclusion of discrimination measures is an achievable goal for NCHS.

Most important contributions. No nationally representative benchmark study collected on a regular time frame containing self-reported discrimination measures and their associations with health is currently available. Collecting nationally representative data on interpersonal discrimination is feasible and urgently needed. Thus, an important role for NCHS to play in research and surveillance related to discrimination is to collect nationally representative data on a regular basis

A national benchmark study that regularly collects measures of discrimination is needed by a wide range of users. Ongoing regular collection of measures of discrimination will allow scholars to disentangle secular trends from changes over cohorts and differential perspectives across age groups (Gee, Walsemann and Brondolo 2012). This regular collection will permit local communities to have national benchmark data on discrimination for comparison in community studies. CDC Minority Health and Health Equity Science Team Lead Rashid Njai, PhD, MPH, indicated that there are many studies at the state and local level using the Everyday Discrimination Scale that need a national benchmark against which to compare their locality.

Contribution for NCHS Surveys to Discrimination Research and/or Surveillance. As an important psychosocial stressor, inclusion of measures of discrimination on NHIS, NHANES, and NSFG will allow researchers and the public health community to evaluate how discrimination is related to a broad range of health outcomes in national samples and for subgroups of interest. Thus, including a well-validated and well-studied measure of discrimination on NCHS surveys will be an important contribution to research on the impact of discrimination more generally. To be an effective surveillance measure, self-reports of experiences of discrimination need to be regularly collected over time, analyzed across important subgroups of the population, and examined for signals of changes in these measures.

A second contribution that NCHS can make to research and/or surveillance of discrimination is to expand measures beyond discrimination to mechanisms by which repeated experiences of unfair treatment may "get under the skin." Discrimination, including interpersonal racism, shape individuals' experiences of everyday life, leading to a state of anticipatory stress and vigilance during social interactions (Goosby, Cheadle and Mitchell 2018; Lewis, Cogburn and Williams 2015).

There are other underlying constructs that have been studied less often, but that the Workgroup finds may be useful in understanding the mechanisms by which discrimination affects health. Capturing more of these constructs would provide greater insight, however the Workgroup recognizes the limited time that any survey may feasibly and logistically be able to devote to the collection of these measures. For instance, a measure of vigilance is a more novel, less studied measure in the literature, but anticipatory stress and vigilance is considered to be the process by which experiences of racism and discrimination more generally manifest in physiological effects (Goosby, Cheadle and Mitchell 2018). Additionally, vigilance may lead some subgroups to perceive experiences as discrimination more often than others, leading to different levels of reports of experiences of discrimination (and possibly variation in psychometric properties of discrimination scales) (Gaston and Jackson 2021). The Workgroup notes that vigilance alone should not be measured without also measuring discrimination. The subject matter experts indicated that the Everyday Discrimination and Vigilance scales predict health outcomes above and beyond — and are moderated by — race/ethnicity and gender. This association is dose-dependent, suggesting that measuring an underlying continuum of experiences of discrimination is important. These associations are robust and persist after researchers control for relevant risk factors.

Health Care or General Discrimination. We find that both global experiences of discrimination and within the healthcare context are likely to be important contributors to health outcomes. Because not all US adults regularly visit health care settings, asking **only** about discrimination in health care settings is likely to not be applicable to all respondents. As a result, we believe that a limited scope may miss ongoing experiences of discrimination that may affect health. Thus, experiences of discrimination across multiple domains, which needs to include but not be limited to health care settings, is important.

Similarity of Discrimination Content Across Surveys. Because key survey variables differ across NCHS surveys, having similar items on discrimination across surveys will be valuable. Specifically, it would be valuable to have a small core set of identical questions asked on all NCHS surveys. If space permits a longer evaluation with additional measures in one of the surveys, employing common discrimination questions would enable scholars to combine information across surveys.

How many questions should be included in each survey requires information that is beyond the scope of this Workgroup and will be informed by multiple decision points. The first decision point is related to which constructs are to be measured. The Workgroup identified two potential constructs of interest that we find to be useful to include in NCHS surveys – unfair treatment or discrimination, largely measured through the Everyday Discrimination scale, and heightened vigilance, a combination of impression management, social avoidance, and heightened awareness of one's environment, (Hicken, Lee and Hing 2018; Williams and Mohammed 2009).

The second decision point is how many items are needed to adequately measure the breadth of these selected constructs. Because discrimination is a multidimensional construct, a single question is unlikely to measure the breadth of an individual's experiences of discrimination (Williams and Mohammed 2009). The minimum number of items is likely to depend on the discrimination scale(s) that are selected and which items explain the most variance for that scale. The numbers and types of items that are "optimal" may vary across subgroups, including across racial/ethnic subpopulations and age groups (Lewis et al. 2012). Additionally, the Workgroup understands that the Collaborating Center for Questionnaire Design and Evaluation Research (CCQDER) at NCHS is currently evaluating items related to discrimination. Cognitive work, field tests, and other question evaluations done by CCQDER will likely yield important insights into these questions that the Workgroup anticipates will inform how to administer the items in NCHS surveys.

The final decision point is related to survey operations. The NHIS, NHANES, and NSFG may have different "real estate" (i.e., space in terms operational practicalities and resources) on the questionnaire that can be allocated to these important social determinants of health questions. Any survey question that is added related to discrimination and/or vigilance requires programming time, survey administration time, and post-processing time for public release. The Workgroup recognizes these constraints, and that such constraints are outside the Workgroup's scope. Furthermore, adding items to a survey risks increasing the burden to the respondent, potentially affecting survey breakoffs or data quality.

Part B. Methodological Considerations.

One-stage or two-stage approach to measuring discrimination. There are multiple scales that have been developed to measure discrimination, including the Everyday Discrimination Scale, the Experiences of Discrimination Scale, the Schedule of Racist Events, the Major Experiences of

Discrimination Scale, the Racism and Life Experiences Scale, and the Index of Race-Related Stress (Williams and Mohammed 2009). The most commonly used measure of discrimination is the Everyday Discrimination Scale. The Everyday Discrimination Scale uses a two-stage approach, in which respondents are first asked about their perceptions of a variety of experiences (e.g., treated with less courtesy or respect, receive poorer service than others at restaurants or stores, people act as if they think you are not smart), and then asks separately about the "main reason" for the collection of these experiences. This two-stage approach thus does not explicitly ask about whether these experiences are because of an individual's race, but allows the respondent to provide the attribution of race/ethnicity (and possibly other attributions) as they see fit. Some studies only ask about the experiences with discrimination without asking for an attribution. In contrast, a one-stage approach asks about whether an individual experienced unfair treatment because of their race/ethnicity, combining the experiences with the attribution in one question.

Whether to assess discrimination using a one-stage approach versus a two-stage approach is a key methodological decision (Lewis, Cogburn and Williams 2015; Shariff-Marco et al. 2011). Discrimination measures that use a two-stage approach allow an assessment of experiences of discrimination followed by a reported perceived reason for discrimination. Reported rates of racial/ethnic discrimination differ when administered using one-stage and two-stage approach (Shariff-Marco et al. 2011), and explain different variance in health outcomes. Attribution of experiences of discrimination to age, sex, or race changes over the life course and differs for Black and White women (Gee et al. 2019; Gee, Walsemann and Brondolo 2012).

"Check all that apply" attribution. Assessing the reason for discrimination separately from experiences of discrimination could allow the respondent to provide multiple reasons for their experiences (Seng et al. 2012). Research examining the association between discrimination and health effects indicates that the *specific* attribution for experiencing discrimination appears to be less important in explaining health outcomes than reporting *multiple* attributions (Grollman 2014; Seng et al. 2012). Thus, if attributions are measured, allowing respondents to endorse multiple attributions is important. The Workgroup notes, however, that check-all-that-apply questions are not considered to be best practice in questionnaire design for self-administered questionnaires (Smyth et al. 2006).

Intersectional approach. Individuals have multiple social identities that interact and shape interpersonal interactions, and are shaped by social contexts. Understanding how these multiple social identities shape the relationship between discrimination and health is critically important. Many of the existing discrimination scales are agnostic toward the perceived cause of discrimination – and indeed may be attributed to many perceived causes. It is worth examining through cognitive testing or other qualitative work whether the items contained in existing discrimination scales reflect experiences of unfair treatment for individuals who have varying combinations of social identities.

Mode of Administration. Measures of discrimination have been assessed using both self- and interviewer-administration (Paradies 2006). We find few direct or experimental comparisons of

responses to the discrimination scales considered by the Workgroup across interviewer-administered and self-administered modes, and in particular, between face-to-face administration and ACASI administration within an in-person interview. Work by the Pew Research Center showed differences in perceptions of discrimination towards different social groups across web and telephone modes (Keeter et al. 2015). Statistics Canada recently found differences in self-reported discrimination by administration mode (CATI and web) assessed by one question on their General Social Survey, where mode, survey context, and time all changed simultaneously (Hou and Schimmele 2022). **More experimental work is needed to evaluate the effect of mode on reports to discrimination measures.**

Self-reported discrimination seems likely to experience race- or gender-of-interviewer effects, in which systematic shifts in answers are observed when randomly assigned groups of respondents are interviewed by interviewers with different social characteristics. In particular, past research on race and gender-related attitudes shows race- and gender-of-interviewer effects (West and Blom 2017), and it seems likely that discrimination measures will see similar effects for discrimination measures. In fact, Krysan and Couper (2003), in a lab setting, found that the "strongest evidence for race-of-interviewer effects is found in the perceptions of discrimination scale, a set of questions about the existence of unfair treatment or racial discrimination against African Americans" (p. 372), an effect that was attributed to racial deference (that is, Black respondents reported lower levels of discrimination to white interviewers than to Black interviewers). **More work is needed to experimentally compare interviewer-administration to self-administration on measures of discrimination.**

Reference/Recall Period. The most common discrimination scale – the Everyday Discrimination Scale – does not have an explicit reference period, asking respondents to reflect on their (current) day-to-day life with response categories that range from never to almost every day. When asked about recall and reference periods, the subject matter experts indicated that lifetime experiences of discrimination may differ substantially from recent discrimination. Reports of lifetime ("ever" experiencing) discrimination decrease over the life course (rather than increasing, as would be expected over time), suggesting that respondents forget more distant experiences of discrimination (Van Dyke et al. 2021).

Other Aspects of Measurement and Additional Developmental Work. Yes, additional developmental work is needed. We find that there are many areas where additional work by NCHS may be fruitful:

a) There are multiple major scales for discrimination that are applicable for general population surveys and can be asked of adults of all racial/ethnic backgrounds. As noted by Van Dyke, Crawford and Lewis (2021), these scales have not often been explicitly collected in the same survey (Shariff-Marco et al. 2011), limiting our understanding of the relative contribution of each to health outcomes.

b) Different implementations of the same scales in large-scale probability surveys have used different question introductions and different instructions to the respondent. More work is needed to understand the effects of these question introductions.

c) Different implementation of the same scales have used different response options. For instance, some implementations ask respondents to report the frequency of a given activity over a time period (e.g., a few times per month) and others use vague quantifiers (e.g., never to often) (Shariff-Marco et al. 2009; Shariff-Marco et al. 2011).

d) More work is needed on question order effects when assessing discrimination, including placement in the survey and how the context of prior questions may affect answers to these questions.

e) Current discrimination measures may not fully capture the severity of the experience with discrimination (e.g., interaction with police), and may miss important experiences of discrimination (e.g., the CHIS added "people criticized your accent or the way you speak" (Shariff-Marco et al. 2011)). More work is needed on assessing discrimination experience severity and on the relevant domains of unfair treatment.

f) Different items in existing discrimination scales may be understood differently across subgroups (e.g., older vs. younger respondents). We find that cognitive interviews, behavior coding, or other qualitative work may be needed to evaluate the performance of these measures for respondents with a wide range of characteristics (Johnson et al. 2015; Shariff-Marco et al. 2009; Shariff-Marco et al. 2011).

g) Whether respondents (overall and across subgroups) consistently report experiences with discrimination over time needs additional exploration. We find that a reliability study would be useful.

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