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July 10, 2018

ELECTRONICALLY TRANSMITED

Elizabeth M. Jaffee, President
Co-Chairs and Program Committee Members for the 11th AACR Conference on the Science of Cancer Health Disparities in Racial/Ethnic Minorities and the Medically Underserved
American Association for Cancer Research
615 Chestnut St., 17th Floor
Philadelphia, PA 19106-4404

> Re: Problems in Cancer Health Disparities Research and Other Cancer Research Due to the Failure to Understand Patterns by Which Measures Tend to Be Affected by the Prevalence of an Outcome

Dear President Jaffee and Co-Chairs and Program Committee Members for the 11th AACR Conference on The Science of Cancer Health Disparities in Racial/Ethnic Minorities and the Medically Underserved:

The principal purposes of this letter, which is prompted at this time by the July 18, 2018 deadline for abstracts for the 11th AACR Conference on the Science of Cancer Health Disparities in Racial/Ethnic Minorities and the Medically Underserved, is to explain problems in cancer health disparities research due to the failure of researchers to understand patterns by which measures of differences between outcome rates of advantaged and disadvantaged groups tend to be affected by the prevalence of an outcome. A second purpose of the letter is to explain the way that the same failure of understanding undermines analyses of other cancer-related issues, including issues concerning identification of subgroup effects and calculation of the number-needed-to-treat to achieve one favorable outcome.

In quite a few places I have explained that health and healthcare disparities research has been undermined by a failure to recognize patterns by which measures employed in such research tend to be affected by the prevalence of an outcome. See, *e.g.*, <u>Comments for</u> <u>Commission on Evidence-Based Policymaking</u> (Nov. 14, 2016), ¹ "The Mismeasure of Health <u>Disparities</u>," *Journal of Public Health Management and Practice* (July/Aug. 2016), "<u>Race and</u>

¹ To facilitate consideration of issues raised in documents such as this I include links to referenced materials in electronic copies of the documents. Such copies are available by means of the <u>Measurement Letters</u> page of jpscanlan.com. If the online version of the letter is amended, such fact will be noted on the first page of that version.

<u>Mortality Revisited</u>," *Society* (July/Aug. 2014), "<u>Measuring Health and Healthcare Disparities</u>," Proceedings of the Federal Committee on Statistical Methodology 2013 Research Conference (Mar. 2014), "<u>Measuring Health Disparities</u>," *Journal of Public Health Management and Practice* (May/June 2006) (letter), "<u>Can We Actually Measure Health Disparities</u>?," *Chance* (Spring 2006), "<u>Race and Mortality</u>," *Society* (Jan./Feb. 2000), and "<u>Divining Difference</u>," *Chance* (Fall 1994).²

In these and other places, I have explained that, as a result of the failure to recognize the referenced patterns, health and healthcare disparities research involving rates at which advantaged and disadvantaged groups experience some favorable or adverse outcome has invariably failed to attempt to distinguish between the extent to which observed patterns of the comparative size of a measure at different points in time or in different settings are simply functions of the different prevalence of an outcome in the situations examined and the extent to which the patterns reflect something significant about underlying processes. Consequently, virtually all statements made about whether a disparity in some health or healthcare outcome is increasing or decreasing over time, or whether a disparity is otherwise larger in one setting than another, have been unsound and misleading. The same may be said of virtually all inferences drawn about underlying processes or the value of particular polices based on changes in a measure of disparity or the comparative size of a measure in difference settings.

In a July 17, 2017 <u>letter</u> to the Secretary of the Department of Health and Human Services (HHS) (sent also to the Secretary of Education and the Attorney General), I suggested that HHS should halt all funding of research that fails to consider the effects of the prevalence of an outcome on the measure employed.³ See also the fourth recommendation (at 46-47) of the

² About 25 conference presentations with graphical and tabular illustrations of the pertinent patterns may be found here. University workshops with more extensive illustrations include: "<u>The Mismeasure of Health Disparities in Massachusetts and Less Affluent Places</u>," Quantitative Methods Seminar, Department of Quantitative Health Sciences, University of Massachusetts Medical School (Nov. 18, 2015) (abstract); "<u>The Mismeasure of Discrimination</u>," Center for Demographic and Social Analysis, University of California, Irvine (Jan. 20, 2015); "<u>The Mismeasure of Demographic Differences in Outcome Rates</u>" Public Sociology Association of George Mason University (Oct. 18, 2014); "<u>Rethinking the Measurement of Demographic Differences in Outcome Rates</u>," Maryland Population Research Center of the University of Maryland (Oct. 10, 2014); "<u>The Mismeasure of Association</u>: <u>The Unsoundness of the Rate Ratio and Other Measures That Are Affected by the Prevalence of an Outcome</u>," Minnesota Population Center and Division of Epidemiology and Community Health of the School of Public Health of the University of Minnesota (Sept. 5, 2014); "<u>The Mismeasure of Group Differences in the Law and the Social and Medical Sciences</u>," Institute for Quantitative Social Science at Harvard University (Oct. 17, 2012); "<u>The Mismeasure of Group Differences in the Law and the Social and Medical Sciences</u>," Department of Mathematics and Statistics of American University (Sept. 25, 2012).

³ The principal purpose of the July 17, 2017 letter was to explain to the recipient agencies that, contrary to the belief the agencies have promoted through "Dear Colleague" letters and otherwise, generally reducing public school discipline rates tended to increase, not reduce, (a) relative racial differences in discipline rates and (b) the proportion African Americans make up of disciplined students, and to advise the agencies of their obligation to explain to the public and school administrators the ways in which the agencies have misled them. See also my December 8, 2017 testimony to the U.S. Commission on Civil Rights, as well as my "Misunderstanding of Statistics Leads to Misguided Law Enforcement Policies," *Amstat News* (Dec. 2012), and "Things government doesn't know about racial disparities," *The Hill* (Jan. 28, 2014). See also my June 26, 2018 letter to the Maryland State Department of

November 14, 2016 Comments for the Commission on Evidence-Based Policymaking. If HHS were to fully understand the issues addressed in the materials cited above, it would sensibly halt all current HHS-funded or HHS-conducted research that endeavors to determine, for example, whether some health or healthcare disparity is increasing or decreasing over time and what policies have a role in such increases or decreases.

One salient illustration of the disarray in health and healthcare disparities research may be found in the following situation. As early as 2004, the National Center for Health Statistics (NCHS) recognized that as health and healthcare generally improved, relative differences in the increasing outcomes (like survival and receipt of appropriate care) tend to decrease, while relative differences in the corresponding decreasing outcomes (like mortality and nonreceipt of appropriate care) tend to increase. Yet no other arm of the federal government has yet shown an awareness that it is even possible for the relative difference in a favorable outcome and the relative difference in the corresponding adverse outcome to change in opposite directions as the prevalence of the two outcomes changes, much less that NCHS has found that this tends to occur systematically.

The failure to understand this issue is especially evident in research into racial and other disparities in cancer outcomes. For research into disparities in cancer outcomes (almost invariably measured in terms of relative differences, at least in the United States) commonly refers to disparities in survival and disparities in mortality interchangeably, often stating it is examining disparities in survival when it in fact is examining disparities in mortality. Invariably the research does so without recognizing (a) that general improvement in cancer care with associated increases in survival rates tend to reduce relative differences in survival while increasing relative differences in mortality; (b) that more survivable cancers tend to show smaller relative differences in survival but larger relative differences in mortality than less survivable cancers; or (c) that relative differences in survival tend to smaller, while relative differences in mortality tend to be larger, among subgroups with comparatively high survival rates (like younger and healthier subjects) than among subgroups with comparatively low survival rates (like older and less healthy subjects).

See references in second paragraph of this letter (especially the discussion of cancer outcomes in "Measuring Health and Healthcare Disparities"). See also pages 1 to 3 of my <u>Comments for the Commission on Evidence-Based Policymaking</u> (Nov. 28, 2016) (a follow-up to the November 14, 2016 comments referenced in the second paragraph), which discuss a 2016 *Journal of Clinical Oncology* study highlighted in an article on the National Cancer Institute (NCI) website. The study illustrates varied aspects of the failure to recognize that relative differences in adverse cancer outcomes can (and commonly do) yield opposite conclusions from

Education and my April 12, 2018 <u>letter</u> to the Government Accountability Office. Pages 6-7 of the letter to the Government Accountability Office touch upon the waste of resources devoted to unsound health and healthcare disparities research and the role the Government Accountability Office ought to take in addressing the situation.

those yielded by relative differences in favorable cancer outcomes regarding such things as directions of changes over time or the comparative size of demographic differences in outcomes for different stages of cancer. To my knowledge, no published article on demographic differences in cancer outcomes has ever recognized the possibility for relative differences in favorable cancer outcomes and relative differences in the corresponding adverse cancer outcome to yield opposite conclusions about such issues, which suggests that such possibility is unknown to journal editors, statistical consultants, and peer reviewers, as well as the authors of articles.

And, as in the case of the essentially universal belief that generally reducing public school suspensions will tend to reduce, rather than increase, relative racial differences in suspension rates that was addressed in the July 17, 2017 letter to heads of HHS and other agencies (see note 3 *supra*), it is common for articles on demographic differences in cancer outcomes, and commentary thereon, to reflect the mistaken belief that general improvements in cancer care should tend to reduce relative differences in cancer morality. This accords with commonplace belief that a reduction of any type of mortality would be expected to reduce, rather than increase, relative demographic differences in mortality. In the case of cancer outcomes, however, the suggestion that improvements in care would be expected to reduce disparities will often be made with reference to survival disparities. The suggestion will be correct with respect to the relative differences in survival to which it literally refers, but it will be incorrect with respect to the relative differences in mortality that usually are in fact being analyzed.

See the <u>Mortality and Survival</u> page of jpscanlan.com regarding varied situations, usually involving cancer outcomes issues, where observers take for granted that patterns of directions changes in (or the comparative of size of) relative differences in mortality will be the same as the patterns for relative differences in survival. Neither that page not its <u>Updates</u> subpage, however, has been modified since 2013.

Failure to understand these issues also affects discussion of cancer screening disparities issues, where it appears still to be largely unknown that general increases in screening tend to reduce relative differences in rates of receiving screening but increase relative differences in rates of failure to receiving screening. See discussion of Table 3 in "Measuring Health and Healthcare Disparities" regarding a 2009 study in *Cancer Epidemiology Biomarkers & Prevention* that (in reliance on NCHS guidance to measure all healthcare disparities in terms of relative differences in adverse outcomes, *i.e.*, nonreceipt of appropriate care) reported in its abstract as a very large increase in the relative area-socioeconomic difference in mammography what was in fact a very large increase in the relative difference in nonreceipt of mammography but a very large decrease in the relative difference in receipt of mammography. The discussion should be read conjunction with the discussion in "The Mismeasure of Health Disparities" (at 418) of the fact that in 2015 NCHS reversed the recommendation on which the 2009 study relied. Thus, NCHS would now reach an opposite conclusion from that reached in the 2009 study in reliance on NCHS guidance.⁴

⁴ See "The Mismeasure of Health Disparities," "Race and Mortality Revisited," and the "Measuring Health and Healthcare Disparities" regarding the fact that NCHS's recognition that relative differences in favorable health and

It is the failure to understand the pattern whereby the rarer an outcome the greater tend to be relative differences between rates of experiencing it and the smaller tend to be relative differences between rates of avoiding it that is most pertinent to cancer disparities research issues. Sometime, however, cancer disparities issues are analyzed in terms of absolute (percentage point) differences between rates. In such circumstances conclusions about such things as the changes in the size of disparities over time are unaffected by whether one examines the favorable or the adverse outcome. But, as discussed in the post-2005 references in the second paragraph, absolute differences tend also to be affected by the prevalence of an outcome, though in a more complicated way than the two relative differences. Roughly, as uncommon outcomes (below 50% for both groups being compared) become more common, absolute differences between rates tend to increase; as common outcomes (above 50% for both groups) become even more common, absolute differences tend to decrease. The prevalence-driven direction of change of the absolute difference is harder to predict when the outcome is neither common nor uncommon or moves between categories of prevalence during a period examined.

With regard to cancer disparities issues, putting the complexities aside, general increases in procedures including screening will tend to increase absolute differences for uncommon procedures and reduce absolute differences for common procedures. This also means that higher-performing institutions will tend to show larger absolute differences for uncommon procedures, but smaller absolute differences for common procedures, than lower-performing hospitals.⁵ And improvements in cancer outcomes will tend to increase absolute differences in cancer survival (and mortality) where survival rates are generally low but reduce absolute differences where cancer survival rates are generally high.⁶

There will be many departures from the prevalence-related patterns describe above and in the references in the second paragraph. But the patterns must be understood for researchers to attempt to distinguish between the extent to which observed patterns as to the comparative size

healthcare outcomes and relative differences in the corresponding adverse health and healthcare outcomes commonly change in opposite directions as the prevalence of an outcome changes did not result in the agency's providing useful guidance on the measurement of health and healthcare disparities. See Section C.1.d. of "Measuring Health and Healthcare Disparities" (at 29) regarding the failure of the NCI even to recognize that NCHS recognized that relative differences in favorable health and healthcare outcomes and relative differences in the corresponding adverse health and healthcare outcomes tend to the change in opposite direction as the prevalence of an outcome changes, as well as NCI's failure otherwise to provide useful guidance on the measurement of disparities involving cancer outcome and care (including screening) issues.

⁵⁵ See the discussion at pages 337-339 of "Race and Mortality Revisited" regarding the way that reliance on the absolute difference between rates to measure healthcare disparities without consideration of the way the measure tends to be affected by the prevalence of an outcome led Massachusetts to include a healthcare disparities element in its Medicaid pay-for-performance program and to do so in a way that will tend to increase healthcare disparities. See also the University of Massachusetts Medical School Seminar cited in note 2 *supra*.

⁶ See note 19 (at 18) of "Measuring Health and Healthcare Disparities" regarding contrasting interpretations of patterns of changes in demographic differences in cancer outcomes in the United States and in the United Kingdom, where survival disparities are commonly analyzed in terms of absolute differences between rates.

of a measure at different points in time or in different setting are simply functions of the different prevalence of an outcome in the situations examined and the extent to which the patterns reflect something significant about underlying processes. As with other research into demographic differences in health and healthcare (and other) outcomes, to my knowledge, no research into cancer care and outcome disparities issues has yet sought to do this, even when such research has not conflated relative differences in survival with relative differences in mortality.

Implicit in the above-described pattern by which relative differences tend to be affected by the prevalence of an outcome is a pattern by which a factor that affects an outcome rate for two groups with different baseline rates will tend to cause a larger proportionate change in the outcome for the group with the lower baseline rate for the outcome while causing a larger proportionate change in the opposite outcome for the other group. See "Race and Mortality Revisited" (at 339-341) and Section I.d (at 41-43) of the November 14, 2016 Comments for the Commission on Evidence-Based Policymaking. See also my <u>Comment on FDA Proposed</u> <u>Subgroup Regulations</u> (May 16, 2014), <u>Comment on European Medicines Agency Subgroup</u> <u>Guidelines</u> (July 31, 2014), and the <u>Subgroup Effects</u> subpage of the <u>Scanlan's Rule</u> page of jpscanlan.com. Thus, for example, an intervention that improves cancer survival will commonly cause a larger proportionate reduction in mortality, but a smaller proportionate increase in survival, among younger subjects than older subjects.

Subgroup analyses, however, are commonly conducted based on the assumption that, absent a subgroup effect, one will observe the same proportionate effect across all baseline rates for an outcome. That assumption is illogical as well as incorrect, given that it is impossible for a factor to cause equal proportionate changes in two groups' rates of experiencing an outcome while at the same time causing equal proportionate changes in the two groups' rates of experiencing the opposite outcome.

Given that cancer mortality/survival rates are in ranges where researchers in fact may analyze either the effect on survival or the effect on mortality, one might expect that the failings of the standard approach to identifying subgroup effects would be more commonly recognized in analyses regarding cancer outcomes than in analyses regarding other outcomes. But I have not seen such recognition in cancer outcomes research just as I have not seen it in other types of research.

In any case, the difference between the focus on an intervention's effect on cancer survival or its effect on cancer mortality has important clinical implications. For the standard approach to employing an observed effect in a clinical trial to estimating the number-needed-totreat (NNT) to achieve one favorable result in circumstances involving a different baseline rate from that of subjects in a clinical trial is to apply the proportionate effect observed in the trial to the baseline rate of the group to which the subjects being considered for treatment belong. As with calculations of NNT regarding other types of outcomes, the result can vary dramatically depending on whether one applies the proportionate effect that was observed in the clinical trial for the favorable outcome of the proportionate effect that was observed for the adverse outcome. The difference with cancer outcomes issues, however, is that the rate ranges at issue, and the

terms of discussion, are frequently such that researchers and practitioners may in fact rely on either the observed proportionate effect on survival or the observed proportionate effect on mortality, though probably without recognizing the substantial difference in NNTs yielded by the different approaches.

As with cancer disparities research, however, the key thing to understand in analyses of results of clinical trials is that standard measures can be useful only if employed with recognition of the way they tend to be affected by the prevalence of an outcome, as well as the need to identify measures unaffected by the prevalence of an outcome (such as discussed in "Race and Mortality Revisited" or improvements thereon).

Finally, attached to this letter is my July 6, 2018 <u>letter</u> to the Director of the National Institute on Minority Health and Health Disparities (NIMHD) and Members of the National Advisory Council on Minority Health and Health Disparities. That letter addresses issues similar to those addressed here, while also highlighting certain misunderstandings in cancer outcomes disparities research. It does so in the context of suggesting that the upcoming NIMHD Health Disparities Research Institute will harm young researchers by encouraging them to engage in health disparities research while failing to advise them of the problematic nature of such research. I note that the AACR cancer disparities conference will be providing some funding attendance of young cancer disparities researchers as a means of encouraging their interest in cancer disparities research. While that funding is a minor matter, the point of the July 6, 2018 NIMHD letter that encouraging young researchers to engage in a type of research, while failing to advise of the problematic nature of the research, may cause those researchers to devote substantial proportions of their professional lives to unsound research applies to many aspect of the upcoming conference and many activities of the American Association for Cancer Research generally, and not merely with respect to young researchers.

All of these issues should be borne in mind in the appraisal of abstracts for the AACR conference that address matters to which the above issues are pertinent but that fail to show an understanding of those issues.

Sincerely,

/s/ James P. Scanlan

James P. Scanlan

cc: Norman E. Sharpless, Director, National Cancer Institute and ACCR Conference Keynote Speaker

Attachment

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July 6, 2018

ELECTRONICALLY TRANSMITED

Emilio J. Perez-Stable, Director Members of the National Advisory Council on Minority Health and Health Disparities: National Institute on Minority Health and Health Disparities National Institutes of Health 6707 Democracy Boulevard, Suite 800 Bethesda, MD 20892-5465

Subj: Failings in the Teaching at the Health Disparities Research Institute and Consequences of Those Failings for Young Researchers

Dear Director Perez-Stable and Members of the National Advisory Council on Minority Health and Health Disparities:

The purpose of this letter is to advise the National Institute on Minority Health and Health Disparities (NIMHD) of the harms it will do to young researchers as a result of failings in the teaching at the Health Disparities Research Institute (HDRI), which is scheduled to take place between from July 23 to July 27, 2018, and to suggest ways that the institute may actually benefit the participants.

In quite a few places I have explained that health and healthcare disparities research has been undermined by a failure to recognize patterns by which the measures employed in such research tend to be affected by the prevalence of an outcome. See, e.g., "Measuring Health and Healthcare Disparities,"¹ e Proceedings of the Federal Committee on Statistical Methodology 2013 Research Conference (Mar. 2014), "Race and Mortality Revisited," Society (July/Aug. 2014), "The Mismeasure of Health Disparities," Journal of Public Health Management and Practice (July/Aug. 2016), and Comments for Commission on Evidence-Based Policymaking (Nov. 14, 2016).

In these and other places, I have explained that, as a result of the failure to recognize these patterns, health and healthcare disparities research involving rates at which advantaged and disadvantaged groups experience some favorable or adverse outcome has invariably failed to

¹ To facilitate consideration of issues raised in documents such as this I include links to referenced materials in electronic copies of the documents. Such copies are available by means of the <u>Measurement Letters</u> page of jpscanlan.com. If the online version of the letter is amended, such fact will be noted on the first page of that version.

attempt to distinguish between the extent to which observed patterns as to the comparative size of a measure at different points in time or in different setting are simply functions of the different prevalence of an outcome in the situations examined and the extent to which the patterns reflect something about underlying processes. Consequently, virtually all statements made about whether a disparity in some health or healthcare outcome is increasing or decreasing over time or whether a disparity is otherwise larger in one setting than another have been unsound and misleading. The same may be said of virtually all inferences drawn about underlying processes or the value of particular polices based on changes in a measure of disparity or the comparative size of a measure in difference settings.

In a July 17, 2017 <u>letter</u> to the Secretary of the Department of Health and Human Services (HHS) (sent also to the Secretary of Education and the Attorney General), I suggested that the HHS should halt all funding of research that fails to consider the effects of the prevalence of an outcome on the measure employed.² See also the fourth recommendation (at 46-47) of the November 14, 2016 Comments for the Commission on Evidence-Based Policymaking. If HHS were to fully understand the issues addressed in the materials cited above, it would sensibly halt all current HHS-funded or HHS-conducted research that endeavors to determine, for example, whether some health or healthcare disparity is increasing or decreasing over time and what policies have a role in such increases or decreases.

The expenditure or substantial federal resources in the production of unsound and misleading research is a major problem, as is the potential for such research to form the basis for misguided policies. But there is an especially pernicious consequence of the failure of teaching at the NHDI to address patterns by which measures tend to be affected by the prevalence of an outcome. For, by encouraging young researchers to conduct health and healthcare disparities research, while failing to advise them of the ways that most current such research is problematic – and failing to give them guidance on sound research methods – the NHDI may cause many participating researchers to devote much or all of their professional careers to unsound research. Further, in the event that the government does recognize the wastefulness of most health and healthcare disparities research now being conducted, NHDI participants may months or years in

² The principal purpose of the July 17, 2017 letter was to explain to the recipient agencies that, contrary to the belief the agencies have promoted through "Dear Colleague" letters and otherwise, generally reducing public school discipline rates tended to increase, not reduce, (a) relative racial differences in discipline rates and (b) the proportion African Americans make up of disciplined students, and to advise the agencies of their obligation to explain to the public and school administrators the ways in which the agencies have misled them. See also my December 8, 2017 testimony to the U.S. Commission on Civil Rights, as well as my "Misunderstanding of Statistics Leads to Misguided Law Enforcement Policies," *Amstat News* (Dec. 2012), and "Things government doesn't know about racial disparities," *The Hill* (Jan. 28, 2014). See also my June 26, 2018 letter to the Maryland State Department of Education and my April 12, 2018 letter to the Government Accountability Office. Pages 6-7 of the letter to the Government Accountability Office touch upon the waste of resources devoted to unsound health and healthcare disparities research and the role the agency ought to take in addressing the situation.

the future face a halt in the funding of research to which they have devoted substantial time and effort, often with significant adverse effects on their livelihoods.³

One salient illustration of the disarray in health and healthcare disparities research may be found in the following situation. As early as 2004, the National Center for Health Statistics (NCHS)recognized that as health and healthcare generally improved, relative differences in the increasing outcomes (like survival and receipt of appropriate care) tend to decline, while relative differences in the corresponding decreasing outcomes (like mortality and nonreceipt of appropriate care) tend to increase. Yet no other arm of the federal government has yet shown an awareness that it is even possible for the relative difference in a favorable outcome and the relative difference in the corresponding adverse outcome to change in opposite directions as the prevalence of the two outcomes changes, much less that NCHS has found that this tends to occur systematically.

And, as with the mistaken belief that reducing public school suspensions will tend to reduce, rather than increase, relative racial differences in suspension rates that was addressed in the July 17, 2017 letter to heads of HHS and other agencies (see note 2 *supra*), government policies are almost invariably premised on the belief that generally reducing an adverse outcome will tend to reduce relative demographic differences in rates of experiencing it. This occurs while the agencies proceeding on such belief remain unaware that NCHS long ago reached an opposite conclusion about the effects reductions in an outcome on relative differences in rates of experiencing it.

It is possible that no analyst at NIMHD, and no member of the National Advisory Council on Minority Health and Health Disparities or of the faculty for NHDI, knows that it is even possible for the relative difference in a favorable health or healthcare outcome and the relative difference in the corresponding adverse outcome to change in opposite directions as the prevalence of an outcome changes. It is also possible that most or all such persons share the mistaken, but pervasive, view that reducing an adverse health or healthcare outcome should reduce relative differences in rates of experiencing it.

Unless NIMHD takes concerted action regarding the NHDI curriculum, the young researchers attending the institute are likely to complete the program while not only failing to understand the issues arising from the ways measures tend to be affected by the prevalence of an outcome, but believing that no such issues exist. Thus, among many other misguided undertakings, they may well go on to do research that refers to disparities in cancer mortality and cancer survival interchangeably while utterly unaware – and failing to recognize that the data they examine in fact show – that improvements in survival tend to reduce relative differences in survival while increasing relative differences in mortality, that more survivable cancers tend to show smaller relative differences in survival but larger relative differences in mortality than less survivable cancers, or that interventions that improve survival tend to cause larger proportionate

³ The halting of funding of unsound research actually benefits those conducting the research by reducing the amount of time they waste on misguided projects. But many researchers make important personal plans on the expectation of the continued funding of research projects.

increases in survival, but smaller proportionate reductions in mortality, among older subjects than younger subjects. In addition to the references in the second paragraph of this letter (especially the Federal Committee on Statistical Methodology paper), see pages 1 to 3 of my Comments for the Commission on Evidence-Based Policymaking (Nov. 28, 2016).

While it should be evident that researchers cannot provide useful insight into health and healthcare disparities while not even understanding that the two relative differences can change in opposite directions, the references cited in the second paragraph of this letter make clear that this particular failure of understanding is only part of a much larger problem in health and healthcare disparities research arising from the failure to recognize the ways that all standard measures of health and healthcare disparities involving outcomes rates tend to be affected by the prevalence of an outcome.⁴ See, for example, the discussion at pages 337-339 of "Race and Mortality Revisited" regarding the way that reliance on the absolute (percentage point) difference between rates to measure healthcare disparities without consideration of the way the measure tends to be affected by the prevalence of an outcome led Massachusetts to include a healthcare disparities element in its Medicaid pay-for-performance program and to do so in a way that will tend to increase healthcare disparities. See also my "The Mismeasure of Health Disparities in Massachusetts and Less Affluent Places," Quantitative Methods Seminar, Department of Quantitative Health Sciences, University of Massachusetts Medical School (Nov. 18, 2015) (abstract).

See my July 1, 2015 <u>letter</u> to the Agency for Healthcare Research and Quality regarding the way that the agency's confusion about healthcare disparities measurement issues caused it to identify in the 2010 *National Healthcare Disparities Report* as some of the largest reductions in disparities over a particular period situation where the agency also would regard the disparities to be considerably larger at the end of the period than at the beginning of the period. The letter should be read in conjunction with the discussion in the aforementioned *Journal of Public Health Management and Practice* commentary "The Mismeasure of Health Disparities" of the fact that in 2015 NCHS reversed its guidance on the measurement of healthcare disparities in a way that constituted a repudiation of a decade of *National Healthcare Disparities Reports* and other research that had relied on NCHS's earlier guidance.

See pages 343-344 of "Race and Mortality Revisited" regarding the way that joint efforts of the National Quality Forum, Harvard Medical School, and Massachusetts General Hospital to provide guidance on the measurement of healthcare disparities did a signal disservice to those who trust in the expertise of those entities. This material should be read in conjunction with my August 29, 2018 <u>letter</u> to the National Quality Forum addressing the way that the organization continues to provide manifestly unsound guidance for health and healthcare disparities research.

While the current curriculum of NHDI is almost certain to both undermine healthcare disparities research and detract from the prospects for the participants to become capable health

⁴ The references also make clear that the recognition of the pattern by which the two relative differences change as the prevalence of an outcome changes did not enable the NCHS to provide useful guidance on the appraisal of demographic differences in health and healthcare outcomes.

and healthcare disparities scholars, NHDR can easily alter the situation. Ideally, its faculty would master the concepts addressed in the references in the second paragraph and go beyond mastery of those concepts where appropriate. Whether or not that can be accomplished for the upcoming NHDI, the faculty can certainly address with the attendees that there exist issues concerning the ways measure commonly employed in health disparities research tend to be affected by the prevalence an outcome. And the faculty can stress that useful research must endeavor to distinguish between the extent to which observed patterns as to the comparative size of a measure at different points in time or in different setting are simply functions of the different prevalence of an outcome in the situations examined and the extent to which the patterns reflect something about underlying processes. Doing so will promote the soundness of future health and healthcare disparities research and enable NHDI participants both to make informed judgments about the nature of the issues they wish to study and to study those issues with far greater insight than is currently found in analyses of demographic differences in the law and the social and medical sciences.

The above points are made without actual familiarity with the curriculum of the NHDI but with substantial familiarity with the manner in which the government analyzes health and healthcare disparities and the guidance it provides for the analyses of such disparities. I would, of course, be delighted to learn that issues I assume are being entirely ignored are already part of the curriculum. But I note that, for reasons discussed in the references in the second paragraph, discussions that the relative difference the observer happens to be examining and the absolute difference may provide different conclusions about the comparative size of a disparity at different points in time or in different settings do not address the critical issues and commonly impede understanding of those issues.

Sincerely,

/s/ James P. Scanlan

James P. Scanlan