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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," 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 ipscanlan.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

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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 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

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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. 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 Letter 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