James P. Scanlan Attorney at Law 1529 Wisconsin Avenue, NW Washington, D.C. 20007 (202) 338-9224 jps@jpscanlan.com

May 28, 2014

Harvey V. Fineberg, M.D., Ph.D.
President
Institute of Medicine
National Academy of Sciences
National Academy of Sciences Building
2101 Constitution Ave., NW.
Washington, DC 20007

Victor J. Dzau, M.D. Chancellor for Health Affairs Office of the Chancellor Box 3701, DUMC Durham, NC 97710

Re: Institute of Medicine's Unsound Guidance on Health and Healthcare Disparities Research

Dear President Fineberg and Chancellor Dzau:

This is a follow-up to an exchange with Institute of Medicine (IOM) President Harvey V. Fineberg in June of 2010 and a request that the IOM reconsider whether it can provide useful guidance on health and healthcare disparities research without recognizing the patterns by which standard measures of differences between outcome rates tend to be affected by the prevalence of an outcome.

I first raised this matter in a <u>letter</u>¹ to President Fineberg dated June 1, 2010, which is available online with active electronic links, but which is also enclosed. In the letter, which referenced what was then the IOM's most recent effort to provide guidance on health and healthcare disparities research, *Future Directions of the National Healthcare Quality and Disparities Report* (April 24, 2010), I suggested that IOM's guidance on health and healthcare disparities research was unsound as a result of IOM's failure to identify and address certain crucial measurement issues.

¹ As in the case of the earlier letter, underlining of various references in this letter reflects the fact that, in order to facilitate review of those references, links to the references are provided in an electronic copy of this letter posted on the Institutional Correspondence subpage of the Measuring Health Disparities page of jpscanlan.com.

Referencing a range of published work by myself and others, I explained that all health disparities research had been undermined by failure to consider patterns whereby, solely for reasons related to features of the underlying risk distributions, each standard measure of difference between outcome rates tends to be systematically affected by the overall prevalence of an outcome. The most notable of these patterns is that whereby the rarer an outcome, the greater tends to be the relative difference in experiencing it and the smaller tends to be the relative difference in failing to experience it. Thus, as mortality declines, relative differences in mortality rates tend to increase while relative differences in survival rates tend to decrease. As beneficial healthcare procedures like mammography and immunization become more widely available, relative differences in receiving them tend to decrease while relative differences in failing to receive them tend to increase. Absolute differences between rates and differences measured by odds ratios tend also to change systematically as the overall prevalence of an outcome changes, though in more complicated ways than the two relative differences. Roughly, as uncommon outcomes (less than 50% for both groups being compared) become more common, absolute differences between rates tend to increase; as common outcomes (greater than 50% for both groups) become even more common, absolute differences tend to decrease. As the prevalence of an outcome changes, differences measured by odds ratios tend to change in the opposite direction of absolute differences between rates.

As most recently discussed in Section C.1.e (at 29-30) of my Federal Committee on Statistical Methodology (FCSM) 2013 Research Conference paper "Measuring Health and Healthcare Disparities," the IOM Future Directions report reflected no understanding whatever that disparities measures may be affected by the prevalence of an outcome.² And, although the IOM report mentioned relative differences in favorable and adverse outcomes with respect to the manner in which the Agency for Healthcare Research and Quality measured disparities in the National Healthcare Disparities Reports, and discussed that relative and absolute differences may yield different conclusions as to directions of changes in disparities over time, it expressed no awareness that it was even possible for the two relative differences to yield opposite conclusions as to directions of changes over time, much less that they tend to do so systematically. The report failed to express such awareness even though the two relative differences would have yielded different conclusions in the hypothetical the report used to illustrate the possibility that relative and absolute differences could yield different conclusions, and even though the report relied on a 2005 National Center for Health Statistics (NCHS) monograph that specifically noted that determinations of whether health and healthcare disparities are increasing or decreasing would commonly turn on whether one measured

² The failure of IOM treatments of health and healthcare disparities issues to recognize that measures tend to be affected by the prevalence of an outcome was previously treated in my February 4, 2013 *BMJ* comment "<u>The need for new thinking about how to measure disparities</u>." That failure is also addressed in my forthcoming "Race and Mortality Revisited," *Society* (July/Aug. 2014)

disparities I terms of relative differences in favorable outcomes or relative differences in the corresponding adverse outcomes.³

Most important, the *Future Directions* report's handling of measurement issues – as perhaps best reflected by its stressing the importance of providing information on relative and absolute differences when they yield different conclusions concerning things like directions of changes in disparities over time, with the implication that the contrasting interpretations are both in some sense valid – reflects a failure to understand the purpose of examining differing outcome rates of advantaged and disadvantaged demographic groups. That purpose is to understand the forces causing the rates to differ (including the components of those forces), whether those forces are increasing or decreasing over time, what causes them to increase or decrease over time or otherwise to be stronger in one setting than another, and what the comparative strength of the forces in different settings may suggest about related subjects. See page 12 of the FSCM paper.

President Fineberg's June 18, 2010 <u>response</u> to me (available online but also enclosed), after noting that the *Future Directions* report reflected a consensus among experts in a wide range of disciplines, stated:

During committee deliberations, committee members discussed the measurement of disparities and utilized numerous academic sources, including your personal website. As is evidenced in the report text, the committee evaluated whether AHRQ should present disparities in terms of relative or absolute differences, and concluded that "In concert with one another, absolute and relative differences can provide a more comprehensive picture of a disparity than either method alone." Thus, the committee did not recommend a single approach to measuring disparities and instead suggested that when both absolute and relative differences cannot be presented in the National Healthcare Disparities Report, that AHRQ might include absolute rates in graphs and tables and include commentary about whether the relative disparity is changing.

The topics that you raise about the overarching field of disparities measurement and about AHRQ's overall funding mechanisms extend well beyond the committee's task.

It is not clear whether President Fineberg's letter was intended to express the view that presenting both relative and absolute differences resolved the issues I raised (as suggested by the first quoted paragraph) or the view that the issues I raised involved an examination of measurement issues at a depth that was beyond the committee's task (as suggested by the second quoted paragraph). The former interpretation would indicate a fundamental misunderstanding of the issues raised in my letter. It would also indicate the same misunderstanding of the purpose of examining differences in outcome rates that is reflected by language in the report itself to the effect that presenting one of the relative differences and the absolute difference satisfactorily addresses measurement issues.

³ The NCHS reached that conclusion based on my "Race and Mortality," *Society* (Jan. /Feb. 2000). The 2014 *Society* article referenced in note 2 is an updating of the 2000 piece.

If the latter interpretation was intended, such response might be defensible if there existed no significant measurement issues concerning the *National Healthcare Disparities Reports* and if IOM made no effort to provide guidance on such issues. But there are significant issues concerning measurement in the healthcare disparities reports. These include whether either of the two relative differences or the absolute difference can provided useful information concerning whether the forces causing outcome rates to differ have changed over time, given that each measure tends to change solely because the prevalence of an outcome changes. They also include whether, even assuming either relative difference could provide useful information as to how those forces are changing, which relative difference one should employ.

Further, the IOM report did in fact attempt to provide measurement guidance. But in doing so, it failed to show any recognition that there exist either issues concerning the ways measures tend to change solely because the prevalence of an outcome changes or issues arising from the possibility or likelihood that that two relative differences will commonly change in opposite directions. By discussing measurement approaches without recognizing these issues, the IOM report did not merely fail to provide guidance on such issues. Rather, it led those relying on the guidance to believe that no such issues exist and it did so with special force precisely because of the prestige of the IOM and the associated presumption as to its expertise. The IOM's more recent work on health and healthcare disparities issues (such as that discussed in the *BMJ* comment referenced in note 2) further promotes this misunderstanding.

Finally, I note that subsequent to the 2010 exchange health and healthcare disparities measurement issues have assumed even greater importance in light of continuing interest in including healthcare disparities measures in pay-for-performance programs. As discussed at pages 32 to 34 of the FCSM paper, the failure to understand the ways that measures of differences between outcome rates tend to be affected by the prevalence of an outcome has already resulted in a situation where the healthcare disparities element of the Massachusetts Medicaid pay-for-performance program may itself tend to worsen healthcare disparities.⁴

As reflected by the discussion at pages 26 to 32 of the FCSM paper and by the letters referenced at the outset, the criticisms of IOM's guidance on health and healthcare disparities research would apply as well to the activities of countless institution of renown and presumptive expertise that attempt to interpret data on a wide range of subjects in the law and the social and medical sciences. There even exists the perverse situation in civil rights enforcement where federal agencies encourage entities to reduce adverse mortgage lending or public school discipline outcomes in order to reduce relative racial differences in such outcomes while such agencies

_

⁴ See also slides 48 to 52 of my October 17, 2012 applied statistics workshop at Harvard's Institute for Quantitative Social Science "The Mismeasure of Group Differences in the Law and the Social and Medical Sciences" and pages 21 to 24 of my October 9, 2012 Harvard University Measurement Letter. The Massachusetts Medicaid pay-for-performance program is also discussed in the forthcoming "Race and Mortality Revisited" discussed in note 2.

remain utterly unaware of the reasons to expect that reductions in the frequency of an outcome will increase, not reduce, relative differences in rates of experiencing the outcome. ⁵ Institutions interpreting data on demographic differences in academic outcomes do so without evident awareness even that altering a test cutoff (or improving or degrading test performance) will have certain predictable effects on each standard measure of difference between pass and fail rates of advantaged and disadvantaged groups. ⁶

But the fact that the misunderstanding of the ways measures of differences between outcome rates tend to be affected by the prevalence of an outcome is so widespread should not be deemed a justification for IOM's own failures of understanding. It should be deemed a testament to the urgency of IOM's task of correcting those failures.

I therefore urge IOM to review these issues very carefully before it endeavors to make further contributions to the science of health and healthcare disparities research. And I suggest that, on doing so, IOM will see reason to specifically address the failings of its prior guidance. I also urge IOM, in reviewing issues about the ways measures of differences between outcome rates tend to be affected by the prevalence of an outcome, to carefully consider whether those issues have implications in areas beyond health and healthcare disparities research, including clinical areas. See the <u>Subgroup Effects</u> subpage of the <u>Scanlan's Rule</u> page of jpscanlan.com, my February 25, 2013 *BMJ* comment "Goodbye to the rate ratio," and the forthcoming *Society* article referenced in note 2.

Sincerely,

/s/ James P. Scanlan

James P. Scanlan

Enclosures

_

⁵ See my "<u>Misunderstanding of Statistics Leads to Misguided Law Enforcement Policies</u>," *Amstat News* (Dec. 2012), "Standards," *Baltimore Sun* (Aug. 5, 2013), "<u>Things government doesn't know about racial disparities</u>," *The Hill* (Jan. 28, 2014) and the Discipline Disparities and Lending Disparities pages (and subpages) of jpscanlan.com.

⁶ See the <u>Educational Disparities</u> page (and subpages) of jpscanlan.com and the Education Trust and Annie E. Casey Foundation letters cited in the first paragraph of this letter.