

[USCCB comments on the second question of the NIH Request for Information: Inviting Comments and Suggestions on Updating the NIH Mission Statement – “*Suggestions for specific language that could be added to the proposed mission statement and why*” – submitted November 22, 2023]

On behalf of the United States Conference of Catholic Bishops (USCCB), we thank NIH for the opportunity to comment on the important matter of its amending its mission statement, and welcome efforts to improve it to include all marginalized persons. Concerned with the equal innate dignity of every human being, we recommend restoring the express goal of “lengthen life” into the NIH mission statement. The proposed deletion of these words may risk giving the public the incorrect impression that NIH works to preserve the “quality of life” but not also life itself, a situation in which the lives of some individuals would “count” more than those of others, based on the determination of some authority. This is especially problematic in light of the proposed new mission statement’s deletion of “disability” as well. To be sure, we understand that the deletion of “disability” itself was proposed upon the recommendation of the Advisory Committee’s Subgroup on Individuals with Disabilities as a means of increasing inclusivity. The report of that same subgroup that made that recommendation, however, also proposed language that retained the words “lengthen life.” See Report of the Subgroup on Individuals with Disabilities, Advisory Committee to the Director Working Group on Diversity, NIH, Dec. 1, 2022, p. 15 (stating “The NIH should revise the mission statement to be, ‘To seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce illness.’”). The deletion of the words “lengthen life,” itself problematic and seemingly unexplained in the notice and request for information, risks significantly altering the meaning of the deletion of “disability,” compounding the problematic nature of the deletion of “lengthen life.” In other words, we are deeply concerned that the proposed deletion of “lengthen life,” especially in light of the proposed deletion of “disability,” risks promoting a value system in which the lives of individuals with disabilities are discounted on account of perceived, problematic notions of “quality of life.” This would, in fact, directly contradict the “Discrimination on the Basis of Disability” regulations recently proposed by HHS under Section 504 of the Rehabilitation Act, regulations that, among other things, condemn and seek to remedy real and prevalent biases in the health care system that undervalue the quality of life of persons with disabilities and thereby discriminate against such persons even in matters of life and death. See 88 Fed. Reg. 63392, et seq. In order to protect the equal valuation of lives of human beings from discrimination in the health care system, and to not contradict HHS’s own proposed regulations, NIH’s proposed mission statement amendments should restore “lengthen life” as an express goal. Additionally, while we would not second-guess the advisory subgroup’s dissatisfaction with the existing phrasing in the mission statement that makes it a goal “to ... reduce ... disability,” we would offer whether potential alternatives, such as “alleviate the impact of disability” could also be considered by NIH and its advisory groups, so as to maintain express reference to disabilities but in an updated manner. Thank you for your time and consideration.

USCCB, Office of General Counsel