

United States Senate

WASHINGTON, DC 20510-0908

January 24, 2024

The Honorable Monica Bertagnolli
Director
National Institutes of Health
9000 Rockville Pike
Bethesda, MD 20892

Dear Director Bertagnolli:

The National Institutes of Health (NIH) funds critical research that aims to address some of the most important health challenges of our time. Researchers, physicians, policymakers, and patients alike all look to the agency's mission and work to inform their approach to healthcare. On August 25, 2023, your agency released a proposed change to its mission statement that would, among other things, remove "lengthen life" from NIH's stated goals.¹ We write to express concern about the potential effects of this change and to request information as to why this change was made.

Amid the rising openness of some countries, such as Canada² and the Netherlands,³ as well as a handful of states⁴ toward physician-assisted suicide, we are concerned that eliminating the stated goal of lengthening life within the NIH's mission statement without explanation or justification could have a negative impact on people's existing attitudes towards the quality of life of people with disabilities. People with disabilities deserve to be treated with the same dignity and respect as non-disabled people, but stereotypes and bias in the research and healthcare sectors continue to prevent people with disabilities from getting the care they need, when they need it. One survey found that over 80 percent of U.S. physicians who responded said they believe people with a significant disability have a worse quality of life than nondisabled people.⁵ Evidence suggests this could lead to discrimination in how doctors recommend physician-assisted suicide. With such pervasive, harmful views impacting so many Americans, it is imperative that the mission of the nation's biggest funder of biomedical research be crystal clear.

While we applaud the NIH for recognizing the disparity in current healthcare research and delivery for people with disabilities,⁶ we remain concerned about the proposal to remove "lengthen life" from the NIH's overall mission statement. To better understand why NIH is

¹ <https://grants.nih.gov/grants/guide/notice-files/NOT-OD-23-163.html>

² <https://www.canada.ca/en/health-canada/services/publications/health-system-services/annual-report-medical-assistance-dying-2022.html>

³ <https://www.government.nl/topics/euthanasia/euthanasia-assisted-suicide-and-non-resuscitation-on-request>

⁴ <https://apnews.com/article/assisted-suicide-vermont-residency-requirement-10ce4f29063f5bbb1873583f9aa89947>

⁵ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8722582/#:~:text=Our%20survey%20of%20714%20practicing,o,f%20life%20than%20nondisabled%20people>

⁶ <https://nihrecord.nih.gov/2023/10/13/nih-designates-people-disabilities-population-health-disparities>

proposing this change, we request a staff-level briefing to discuss this issue, as well as your response to the following questions:

1. What motivated your decision to remove “lengthen life” from the NIH mission statement?
2. Were outside groups consulted in the decision-making process? If so, which organizations, and what were their recommendations?
3. What, if any, effect will deleting the phrase “lengthen life” have on the work of the NIH in its research and grant-making priorities? What guidance will be provided to program officers and other relevant personnel?

Thank you for your attention to this matter. We look forward to your response.

Sincerely,

A handwritten signature in blue ink, appearing to read 'M. Rubio', with a stylized, cursive script.

Marco Rubio
U.S. Senator

A handwritten signature in blue ink, appearing to read 'Tammy Duckworth', with a stylized, cursive script.

Tammy Duckworth
U.S. Senator