NIH Request for Information: Inviting Comments and Suggestions on Updating the NIH Mission Statement

October

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Report on the Results of the RFI

Introduction

The National Institutes of Health (NIH) is the nation's medical research agency; it conducts and supports research leading to important discoveries that improve health and save lives. NIH's current mission statement⁴ is "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 and disability."

In 2021, NIH established the Advisory Committee to the Director (ACD) Working Group on Diversity, Subgroup on Individuals with Disabilities, ⁵ to identify strategies to support individuals with disabilities. The Subgroup issued a report ⁶ in December 2022 that contains several recommendations, including updating the NIH mission statement. The ACD adopted the Working Group's recommendations and provided them to the NIH Director. The report stated:

- Feedback on whether the proposed new mission statement reflects the goals and objectives as outlined in the NIH-Wide Strategic Plan for Fiscal Years 2021–2025⁸
- Suggestions for specific language that could be added to the proposed mission statement and why
- Feedback on any specific language that could be removed from the proposed mission statement and why

Characteristics of Respondents

NIH received 492 submissions to the RFI. Of those, 98% (480) were classified as responsive. Examples of nonresponsive submissions included blank entries and comments that did not address the RFI questions. The coding and analysis of the public input is based on the 480 responsive submissions.

Of the 480 submissions that were included in the analysis, 82% (395) were from individuals and 11% (54) were from organizations. Respondents, as self-described, were from a variety of professional areas; 35% (167) were scientists and 16% (76) were advocates. Figure 1 shows the affiliated organizations of the respondents, with 28% (134) from academia and 21% (100) from the federal government.

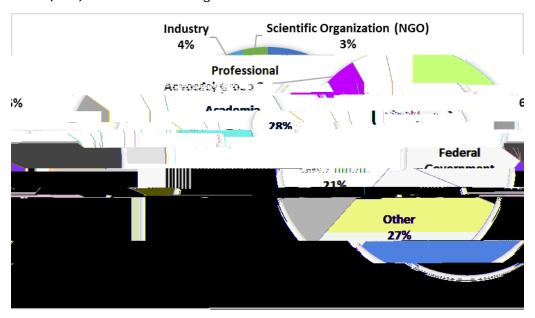


Figure 1. Affiliated organization of respondents (N = 480).

Analysis of Results

Responses to the RFI were accepted through an online form, and input on the three categories was collected using text boxes. NIH staff analyzed the responses using a standardized coding schema and captured relevant language from the responses. Sample responses and a description of the codes used in the analysis are available in Table 1 of the Appendix. Codes were not mutually exclusive, and response statements were assigned to multiple codes as necessary.

https://www.nih.gov/sites/default/files/about-nih/strategic-plan-fy2021-2025-508.pdf

Comments and Suggestions on Reflecting Strategic Plan

Thirty-two percent (154) of respondents commented on whether the proposed new mission statement reflects the goals and objectives as outlined in the current NIH-Wide Strategic Plan. The most common response received was that respondents did feel that the proposed new mission statement reflects the Strategic Plan (20%, 96), and some (4%, 21) felt that it partially reflects the Strategic Plan. A smaller number of respondents (8%, 37) did not feel that the proposed new mission statement reflects the Strategic Plan.

Comments and Suggestions on Language to Add

The majority (76%, 365) of respondents had suggestions for language that could be added to the proposed new mission statement. As shown in Figure 2, 38% (182) suggested that disability should be added back in s w1 (2e)3 ((n)]TJTc -0.007 Tw [4.66 -2.1-07 (lly)-2(w)5 (e)3 (s)28 (t)

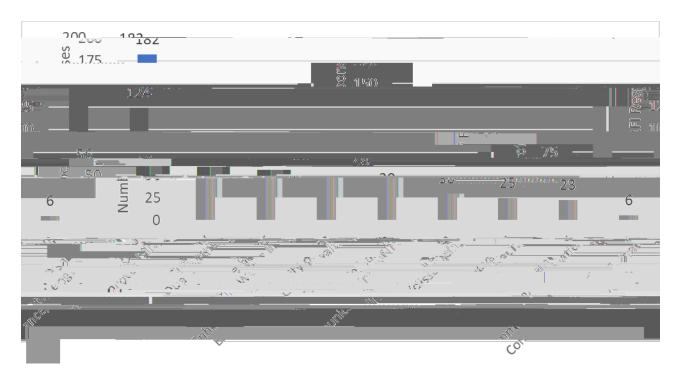
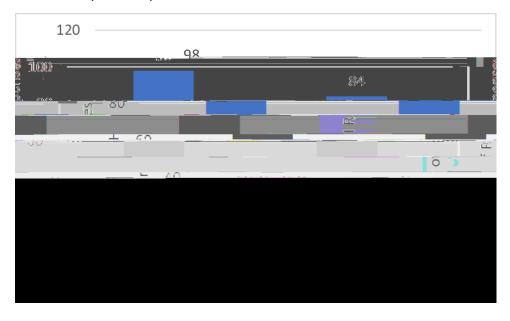


Figure 2. Suggestions for specific language that could be added to the proposed mission statement (N = 480).



Comments and Suggestions on Language to Delete

Twenty-seven percent (130) of respondents suggested language to delete. As shown in Figure 4, the phrase most frequently suggested for deletion was "optimize health" (11%, 51). Respondents' rationales for this deletion included preference for the current language

("enhance health") and potential interpretation of "optimize" as ableist. ⁹ Another suggested deletion was "prevent or reduce illness" (9%, 43), because this phrase was viewed as redundant to "optimize" and could be interpreted as ableist. Language less frequently suggested for deletion was captured in the "other" category (15%, 72). Examples included "fundamental" and "nature and behavior of living systems" because respondents felt the mission statement could be more concise and simplified to make it more relatable for the general public.

Figure 4. Feedback on specific language that could be removed from the proposed mission statement (N = 480).

Summary and Conclusion

The RFI responses received (480) included a range of suggested language to add to or delete from the proposed mission statement. The majority of responses received were from individuals. Various professional roles (scientists, advocates, others) and affiliated organizations (academia, federal government, progressional advocacy groups, others) were represented in the responses received.

Notably, opposing views were expressed in the RFI comments. For example, 38% of respondents felt that disability should be added back into the mission statement in some way. Of those, some (20%) wanted disability included but presented in an alternative way, whereas others (18%) wanted the current "reduce disability" language to be kept in the mission statement. Respondents who identified as being part of the disability community (e.g., having a disability or being a parent of a child with a disability, a member of a disability-focused advocacy organization, or an ally) expressed these opposing views. Another example is that some respondents (12%) felt strongly that the phrase "lengthen life" in the current mission statement should be retained.

Along with coding the specific feedback sought in the RFI, staff also coded the sentiment of each response to gauge how supportive responses were to the proposed mission statement. The majority (62%, 298) of submissions were overall supportive of the proposed mission statement. This included respondents who were supportive of the mission statement as proposed (19%, 92), supportive but with minor suggested changes (22%, 107), and

supportive with major suggested changes (21%, 99). Some responses received were not supportive of the proposed new language (28%, 134) or were neutral (10%, 48).

The rationale provided for being supportive of the proposed mission statement with "reduce disability" removed echoed the ACD report 10 that the current mission statement could be interpreted as perpetuating ableist beliefs that disabled people are flawed and need to be fixed. Some responses also expressed support for the addition of the phrase "for all people" because it highlights NIH's commitment to inclusivity. Examples of responses that were classified as supportive with minor changes included those that suggested replacing "optimize" with "enhance" and those that suggested removing "prevent or reduce illness" because the phrase was redundant to "optimize." Responses that were classified as supportive with major changes included those that applauded the removal of "reduce disability" but a6[(a)19 14 (r)168 (s)-5 (d)2 (r)6 (e)f4 (be)8r (a)28.1t beas rR.

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B09.	"Health" should be expanded to
Well-being	incorporate well-being. Perhaps
	change "health" to "well-being" or to
	"whole person health."

D1.	strongly supports the
2	recommendation to amend the NIH
Supportive of the proposed	
mission statement, with no	mission statement to better support
additional changes suggested	disability inclusion and remove any
	perpetuation "of ableist beliefs that
	disabled people are flawed and need
	to be fixed."
D2.	We recommend removal of this
Supportive, with minor changes	language because we felt that
suggested	"prevent or reduce illness" could fall
	under optimizing health.
D3.	I think that the goals of the suggested
Supportive, with major changes	change to NIH's mission statement
suggested	are good. However, the suggested
	wording eliminates any indication that
	disability research is central to NIH's
	mission. I consider this to an
	unintended consequence that runs
	counter to the many other excellent
	suggestions from the Subgroup on
	Individuals with Disabilities.
D4.	Remove the word "to" in front of
Neutral	optimize to create an ellipsis. The
	second "to" is redundant.
D5.	The proposed change in language in
Not supportive	the mission statement implies that
	NIH is not interested in finding a
	cure for the cause of my disability. I
	want the NIH to help find a cure, so
	I oppose changing the mission
	statement.

Request for Information

Request for Information (RFI): Inviting Comments and Suggestions on Updating the NIH Mission Statement

Notice Number:

NOT-OD-23-163

Key Dates

Release Date: August 25, 2023

Response Date: November 24, 2023

Related Announcements

None

Issued by

National Institutes of Health (NIH)

Purpose

This Notice is a Request for Information (RFI) inviting feedback on a proposed update to the NIH mission statement. As the largest public funder of biomedical and behavioral research in the world, NIH works to turn scientific discoveries into better health for all. This RFI will inform NIH's efforts to update its mission statement to ensure that it reflects the NIH mission as accurately as possible.

Review of this entire RFI notice is encouraged to ensure your response is comprehensive and to have a

Background

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To address this suggestion, NIH Leadership committed to evaluate the mission statement, particularly reviewing the inclusion of the phrase "reduce [...] disability", and to update it to better reflect the current