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

Analysis of Public Comments

October 2024

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Executive Summary

As the largest public funder of biomedical and behavioral research in the world, the National Institutes of Health (NIH) works to turn scientific discoveries into better health for all. NIH's current mission statement¹ 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 2022, NIH's Advisory Committee to the Director (ACD) Working Group on Diversity, Subgroup on Individuals with Disabilities, ² recommended that NIH remove "reduce disability" from its mission statement. Following this recommendation, NIH leadership committed to evaluating the mission statement to better reflect the current and future vision for the agency. A revised mission statement was proposed: "to seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to optimize health and prevent or reduce illness for all people."

NIH sought external and internal input on the proposed revised mission statement through a Request for Information (RFI): Inviting Comments and Suggestions on Updating the NIH Mission Statement (NOT-OD-23-163).³ The RFI collected feedback from August 25, 2023, to November 24, 2023. NIH received 492 submissions to the RFI from individuals and organizations representing academia, the federal government, industry, advocacy and professional groups, and others.

Notably, opposing views were expressed in the RFI comments. For example, 38% of respondents suggested that disability should be specifically mentioned in the mission statement. Of those, some (20%) wanted disability included but presented in a different way, whereas others (18%) wanted the current "reduce disability" language to be retained in the mission statement. Another example is that some respondents (12%) felt strongly that the phrase "lengthen life" in the current mission statement should be retained.

Overall, the RFI revealed that more input is needed to better understand all perspectives before finalizing the mission statement. NIH plans to gather additional community feedback in the coming months.

¹ https://www.nih.gov/about-nih/what-we-do/mission-goals

² https://www.acd.od.nih.gov/working-groups/disabilitiessubgroup.html

³ https://grants.nih.gov/grants/guide/notice-files/NOT-OD-23-163.html

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:

One immediate action for the NIH to support disability inclusion is to remove the language of "reducing disability" from the NIH mission statement. The current mission statement could be interpreted as perpetuating ableist beliefs that disabled people are flawed and need to be "fixed."

To address this suggestion, NIH leadership committed to evaluating the mission statement, particularly reviewing the inclusion of the phrase "reduce [...] disability," and to updating it to better reflect the current and future vision for the agency. Following discussions among NIH leadership and with NIH subject matter experts, a revised mission statement was developed. The bolded language reflects differences between the current and proposed mission statements.

Current mission statement: 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.

Proposed revised mission statement: To seek fundamental knowledge about the nature and behavior of living systems and **to apply** that knowledge **to optimize health and prevent or reduce illness for all people.**

To inform its efforts to update its mission statement to accurately reflect the NIH mission, NIH released a Request for Information (RFI): Inviting Comments and Suggestions on Updating the NIH Mission Statement (NOT-OD-23-163). Public comments were accepted from August 25, 2023, to November 24, 2023.

The RFI invited input on the proposed mission statement from interest groups throughout the scientific research and clinical practice communities, people with lived experiences and organizations that advocate for them, those employed by NIH or at institutions receiving NIH support, and the public. Input sought included the following:

⁴ https://www.nih.gov/about-nih/what-we-do/mission-goals

⁵ https://www.acd.od.nih.gov/working-groups/disabilitiessubgroup.html

⁶ https://acd.od.nih.gov/documents/presentations/12092022 WGD Disabilities Subgroup Report.pdf

⁷ https://grants.nih.gov/grants/guide/notice-files/NOT-OD-23-163.html

- 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.

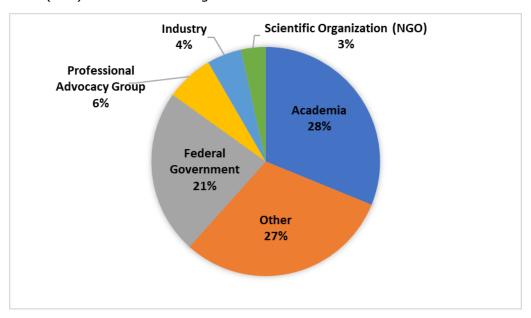


Figure 1. Affiliated organization of respondents (N = 480).

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.

⁸ 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 to the mission statement. This included respondents who applauded the removal of the term "reduce" but felt that disability should be specifically mentioned in some other way (20%, 98), as well as respondents who suggested the current language of "reduce disability" should be retained (18%, 84) (Figure 3). The most frequently suggested alternative way to include disability was to use the phrase "optimize function" (9%, 45). The rationales for suggesting an alternative way to incorporate disability included that the proposed wording implies that disability research is no longer central to NIH's mission. Respondents who wanted the language "reduce disability" to be kept in the mission statement included those who are living with certain types of disabilities or who have a family member living with certain types of disabilities and do want their disabilities to be reduced or cured.

Respondents also suggested that other language in the current mission statement should be retained, specifically "lengthen life" (12%, 56) and "enhance health" (10%, 49) (Figure 2). Suggestions for new language to be added included "quality of life" (6%, 30), "well-being" (5%, 25) and "equity" (5%, 23). Language that was not as frequently suggested as the listed phrases in Figure 2 was captured in the "other" category (26%, 124). Examples of these responses included language around curing diseases, global health, mental health, and research workforce development.

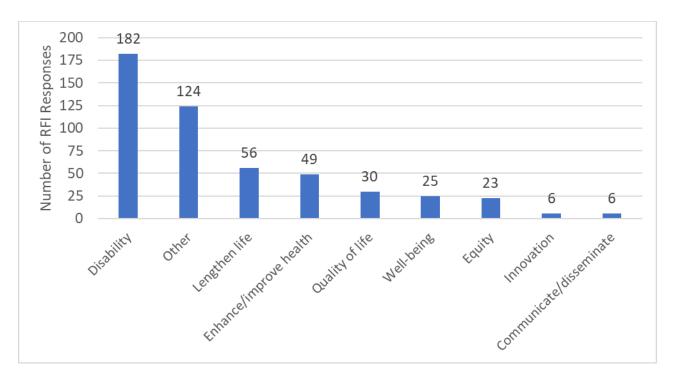


Figure 2. Suggestions for specific language that could be added to the proposed mission statement (N = 480).

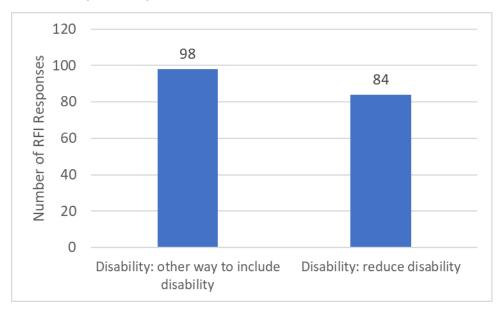


Figure 3. Suggestions for disability-related language that could be added to the proposed mission statement (N = 480).

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.

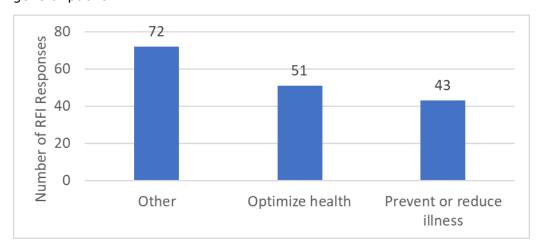


Figure 4. Feedback on specific language that could be removed from the proposed mission statement (N = 480).

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

⁹ Ableism is the belief that people with disabilities are flawed and less valuable than nondisabled people (Villines Z. What is ableism, and what is its impact? *Medical News Today*. November 7, 2021. https://www.medicalnewstoday.com/articles/ableism).

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 advocated for specifically mentioning disability using different language. Responses that suggested that the current language, "reduce disability," be retained were classified as not supportive of the proposed language.

Overall, the RFI revealed that more input is needed to better understand all perspectives before finalizing the mission statement. NIH plans to gather additional community feedback in the coming months.

Acknowledgments

Special thanks to the Mission Statement RFI Coding Team (Rebecca Baker, Lauren Brodd, Brittany Chao, Jacklyn Chen, Robert Eisinger, Tyrone Spady, and Allison Wynne, all in OD/IMOD at the time of coding); Matt Perkins (OD/DPCPSI/OPA); OD/DPCPSI; OD/OCPL; OD/OER/DCO; and NIH subject matter experts on disability-related issues.

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¹⁰ https://acd.od.nih.gov/documents/presentations/12092022 WGD Disabilities Subgroup Report.pdf

Appendix

Table 1. Coding Table and Selected Example Comments

The comments below were taken directly from the RFI responses. Removed text is denoted by ellipses.

Primary Category: A. Reflecting Strategic Plan

Code: Goals and objectives (If the proposed changes reflect the goals and objectives in the Strategic Plan)

Subcode	Selected Example Comments
A1. No response	N/A
A2. Yes, reflects Strategic Plan	As a parent of a child with a disability, I support this change and feel it reflects the stated goals and objectives.
A3. Partially reflects Strategic Plan	While the NIH's newly proposed mission statement advances the goal of ensuring all people are included, the language can be improved to better reflect the objectives and crosscutting themes outlined in the NIH-Wide Strategic Plan.
A4. No, does not reflect Strategic Plan	submits that removal of the term disability from the NIH Mission statement without substituting language that covers critical topics that are not illness-specific is not reflective of the goals and objectives in the NIH-wide strategic plan.

Primary Category: B. Suggested additions

Code: Specific language suggested to be added to proposed statement

Subcode	Selected Example Comments
B01. No response	N/A
то гезропзе	
B02. Lengthen life	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.
B03. Disability: reducing disability	I have had a severe hearing impairment since childhood, and I absolutely want the NIH to focus on reducing disability. Those who think disability does not need to be treated/fixed can opt out of treatments if they'd like to. However, it is utterly unfair of them to try to prevent others from seeking solutions to their disabilities.
B04. Disability: optimize function	While the decision to remove "disability" from the mission statement is sound, the purpose of "reducing disability" is to "improve function," and that should still be part of the NIH mission.
B05. Disability: other way to include disability	The proposed revision eliminates the concept of disability research from the NIH mission. Adding "ability" to the mission statement is intended to maintain an emphasis on the importance of disability research, as highlighted in other portions of the report from the Subgroup on Individuals with Disabilities.
B06. Equity	We believe that moving forward, the NIH must explicitly commit to the goal of equity in its mission statement, as one way to prioritize inclusion in the search for and application of knowledge, health optimization, and illness prevention and reduction across people of all races, ethnicities, disabilities, ages, sexual orientations, and gender identities.
B07. Enhance/improve health	Enhancing health rather than optimizing it takes out the judgement of what IS optimal health, which is different for different individuals.
B08. Quality of life	recommends that NIH consider including the phrase "improve the quality of life" This addition would expand the NIH mission to include research into ways to help individuals with health challenges live healthier lives.

B09.	"Health" should be expanded to
Well-being	incorporate well-being. Perhaps
	change "health" to "well-being" or to
	"whole person health."
B10.	believes that the addition of "to
Communicate/disseminate	communicate" highlights NIH's
	commitment to become a trusted
	resource for findable, accessible,
	accurate, and timely biomedical
	information.
B11.	Consider including an emphasis on
Innovation	interdisciplinary collaboration and
	innovation, as those are key
	components of the strategic plan.
B12.	We propose the addition "to
Other (please explain in comment	collaborate with a diverse workforce"
box)	to address research conduct and
	capacity as well as inclusiveness
	within these objectives.

Primary Category: C. Suggested deletions

Code: Specific language to be deleted from proposed statement

Subcode	Selected Example Comments
C1. No response	N/A
C2. Optimize health	Enhancing health rather than optimizing it takes out the judgement of what IS optimal health, which is different for different individuals.
C3. Prevent or reduce illness	recommends two additional revisions to the proposed mission statement: replacing "optimize" with "protect and improve" and "prevent or reduce" with "alleviate." Both suggestions are intended to remove terms that could be interpreted as ableist.
C4. Other (please explain in comment box)	The phrase "fundamental knowledge about the nature and behavior of living systems" was assessed as lengthy and likely unclear to many laypeople.

Primary Category: D. Overall tone of response

Code: How supportive the response is of the new proposed mission statement

Subcode	Selected Example Comments

D1.	strongly supports the
Supportive of the proposed	recommendation to amend the NIH
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 full understanding of how it will be used.

Background

NIH is the nation's medical research agency — making important discoveries that improve health and save lives. NIH's <u>current mission statement</u> 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 to dedicate time and resources to identify strategies to support individuals with disabilities. The Subgroup issued a report 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:

"One immediate action for the NIH to support disability inclusion is to remove the language of 'reducing disability' from the NIH mission statement. The current mission statement could be interpreted as perpetuating ableist beliefs that disabled people are flawed and need to be 'fixed'."

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 and future vision for the agency. Following discussions among NIH Leadership and with NIH subject matter experts, a proposed revised mission statement was developed.

Information Requested

This RFI invites input from interest groups throughout the scientific research, advocacy, and clinical practice communities, those employed by NIH or at institutions receiving NIH support, and the public, on a proposed revised mission statement. The bolded language reflects differences between the current and proposed mission statements.

Current mission statement:

"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."

Proposed revised mission statement:

"To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to optimize health and prevent or reduce illness for all people."

Input sought about the proposed revised mission statement includes, but is not limited to, the following:

- Feedback on whether the proposed new mission statement reflects the goals and objectives as outlined in the NIH-Wide Strategic Plan for Fiscal Years 2021-2025
- 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

NIH encourages organizations (e.g., patient advocacy groups, professional societies) to submit a single response reflective of the views of the organization or its membership.

How to Submit a Response

All comments must be submitted electronically on the submission website.

Responses must be received by 11:59:59 pm (ET) on November 24, 2023.

Responses to this RFI are voluntary and may be submitted anonymously. Please do not include any personally identifiable information or any information that you do not wish to make public. Proprietary, classified, confidential, or sensitive information should not be included in your response. The Government will use the information submitted in response to this RFI at its discretion. **The Government reserves the right to use any submitted information on public websites, in reports, in summaries of the state of the science, in any possible resultant solicitation(s), grant(s), or cooperative agreement(s), or in the development of future funding opportunity announcements.** This RFI is for informational and planning purposes only and is not a solicitation for applications or an obligation on the part of the Government to provide support for any ideas identified in response to it. Please note that the Government will not pay for the preparation of any information submitted or for use of that information.

We look forward to your input and hope that you will share this RFI opportunity with your colleagues.

Inquiries

Please direct all inquiries to:

Office of the Director, NIH

Email: RFIMissionStatement@nih.gov