# RFI Responses<sup>1</sup>

# Response 1

# **Reflects Strategic Plan**

No response.

### Suggested additions

No response.

#### Suggested deletions

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

Rationale: Fundamental knowledge is not necessary or sufficient to take action.

# Response 2

#### **Reflects Strategic Plan**

Yes.

#### Suggested additions

No response.

#### Suggested deletions

No response.

# Response 3

#### **Reflects Strategic Plan**

I would leave lengthen life in for sure. Also, why not put reduce illness and disability.

#### Suggested additions

"to optimize (and lengthen life and) health and prevent or reduce illness (and disability) for all people."

# Suggested deletions

Add more.

Information has been redacted to maintain privacy and remove inappropriate language.

<sup>&</sup>lt;sup>1</sup> The <u>Request for Information (RFI): Inviting Comments and Suggestions on Updating the NIH Mission Statement</u> sought input on the proposed revised mission statement, including:

<sup>•</sup> 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

<sup>•</sup> Feedback on any specific language that could be removed from the proposed mission statement and why

# Response 4

# **Reflects Strategic Plan**

I agree with the new mission statement and believe it aligns with the goals and objectives of NIH in the Strategic Plan.

### Suggested additions

No further suggestions for the proposed mission statement.

#### Suggested deletions

No further suggestions for the proposed mission statement.

# Response 5

#### **Reflects Strategic Plan**

No response.

#### Suggested additions

I would add "and quality of life" after "optimize health," because some health issues can't be cured/must be lived with and I'm not sure "optimize health" makes that clear enough.

#### Suggested deletions

No response.

# Response 6

#### **Reflects Strategic Plan**

"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."

I like it, would suggest the following addition in brackets.

#### Suggested additions

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

#### Suggested deletions

No response.

# **Response 7**

#### **Reflects Strategic Plan**

I support the removal of "lengthen life."

#### Suggested additions

"...equally for all people"

Adding the word equally to emphasize NIH goal for equality.

#### Suggested deletions

No response.

# Response 8

# **Reflects Strategic Plan**

No response.

#### Suggested additions

"To seek fundamental knowledge about living systems and to apply that knowledge to optimize the health and prevent or reduce illness for all humankind through scientific research and technological innovations."

I think behavior and nature of living systems sounds too limiting. For example, studying climate change or even AI can relate to health but not necessarily the "Behavior and/or nature" of living systems. There is also basic science that may not directly relate to behavior and nature of living systems. I also changed the sentence to include more of what the Director stated in his cover letter.

#### Suggested deletions

Remove/widen the aspects of living systems that NIH wishes to glean information about in its mission.

# Response 9

#### **Reflects Strategic Plan**

Improving the Health of the Nation through discovery, science, research, and implementation.

#### Suggested additions

Improving the Health of the Nation through discovery, science, research, and implementation.

#### Suggested deletions

Improving the Health of the Nation through discovery, science, research, and implementation.

# Response 10

#### **Reflects Strategic Plan**

I like it but would add that we aim to help out health globally.

#### Suggested additions

Suggested addition: "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 around the world."

No response.

Response 11

# **Reflects Strategic Plan**

As an NIH employee for over 20 years this mission statement is good.

### Suggested additions

N/A

# Suggested deletions

Delete the final sentence as is overly specific and actually negates the first portion of the statement. Delete "...including the development and support of medical libraries and the training of medical librarians and other health information specialists."

# Response 12

# **Reflects Strategic Plan**

I think so.

#### Suggested additions

I loved how Dr. Collins would refer to us as the institutes of hope. I think that is one of our core values, giving hope.

#### Suggested deletions

It sounds good to me.

# Response 13

#### **Reflects Strategic Plan**

No response.

#### Suggested additions

No response.

#### Suggested deletions

"Optimize" is simply wrong here. As scientists, we understand that "optimal" is correctly understood as a binary. A thing is optimal or it is less than optimal; there is no such thing as "more optimal." In a literal sense, "optimizing" implies the existence of an objective achievable "optimum" of health or well-being. This is an absurdity. More to the point, it would imply a state unachievable for the average person, much less a person living with disability, for whom we are allegedly rewriting the mission state in the first place.

"Enhance" was really the better choice here. Perhaps it lacks the "corporate speak" tone of "optimize," but it has the advantage of accuracy.

# Response 14

### **Reflects Strategic Plan**

Sorry, I think it can be better. Specifically, the word "optimize" is generally associated with industrial or technical processes as opposed to health outcomes.

### Suggested additions

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

The word "improve" suits better when talking about health. My perception is based on decades of association with pharma, drug development and clinical trials, including NIH.

#### Suggested deletions

No response.

# Response 15

#### **Reflects Strategic Plan**

No response.

#### Suggested additions

....and to apply the knowledge to improve health management for all people.

#### Suggested deletions

optimize—because what is considered optimal can differ widely, and NIH per se cannot "optimize" things for everyone.

prevent or reduce—strategically important and accurate, but sounds like "looking from above" from the view point of general public.

# Response 16

#### **Reflects Strategic Plan**

I understand the rationale of looking upon disability as not a shortcoming and an identity to just be tolerated or accommodated, but an identity to accept as part of our society and be celebrated. I am having a hard time reconciling this thought against actions the US govt and workplaces take that could prevent more people from developing a disability. For example, the push to working in the office from the current President's administration is directly resulting in more people developing a disability through Long COVID. I hope this wonderful sentiment of celebrating those with disability will not be used as an excuse for those in authority to needlessly cause more people to have disabilities and to escape criticism because it could be reframed as an insult to those with disabilities. I appreciate that NIH has been flexible with their workplace policies and are being cognizant of how they could provide more support for those with disabilities.

#### Suggested additions

No response.

I do welcome the new wording "for all people" in replace of "disability." I appreciated the "enhance health, lengthen life" portion of the current statement; I am unsure why that was recommended to change, as life expectancy is an important indicator of a nation's health and not acknowledging that seems like we are accepting or making an excuse for how the US is lagging in life expectancy compared to similarly developed countries. Additionally, "enhancing health and lengthening life" are proactive, have potential built into them, and acknowledges that we can always improve upon and make things better, while "preventing and reducing illness" is more reactive and again seems to accept that negative health outcomes are the norm (which yes there will always be health issues but as NIH we should be striving to make things better for people, not just making things less worse).

# Response 17

# **Reflects Strategic Plan**

No response.

# Suggested additions

Something is needed that focuses on reducing the sequalae/impact of illnesses that cannot be or are not prevented. Also about delaying the onset of diseases, which results in additional disease-free life years and may allow time for new prevention tactics. AKA primary, secondary and tertiary prevention.

Consider this wording (changed in the 2nd half of sentence): To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to optimize health and prevent, delay, or reduce the sequelae of illness for all people.

#### Suggested deletions

No response.

# Response 18

#### **Reflects Strategic Plan**

No response.

#### Suggested additions

I suggest to change the phrase "to optimize health" to "to promote health."

There are various ways of healthy living. It does not make sense to optimize health, which implies there is only one type of healthy living.

#### Suggested deletions

No response.

#### Response 19

#### **Reflects Strategic Plan**

I think the new mission statement more accurately reflects the goals and objectives of the NIH than the previous one.

#### Suggested additions

I have no suggestions.

#### Suggested deletions

No response.

# Response 20

### **Reflects Strategic Plan**

Great mission statement.

#### Suggested additions

If I were to suggest one possible modification, I would use "understanding and knowledge" instead of "knowledge."

#### Suggested deletions

No response.

# Response 21

#### **Reflects Strategic Plan**

The proposed mission statement removes the the goal to lengthen life from the previous mission statement. I'm unsure how I feel about this as the average life expectancy has been on the decrease for the average American. Does the wording, "seek fundamental knowledge about the nature and behavior of living systems" adequately encompass the societal and environmental impacts on our health?

Is "optimize health and prevent or reduce illness" enough, or do we want to promote wellbeing—to include mental, social, emotional, and physical health?

#### Suggested additions

I would like to add to the beginning of the mission statement something social and environmental. Wat I mean is, we are social being—learning about the "behavior of living systems" outside of a social context misses the mark. Our society greatly impacts how and how well we live. Likewise, the environment in which we live is one of the greatest determinants of our Health outcomes. I believe that needs to be intensely studied.

#### Suggested deletions

Nothing to remove, perhaps things to add from above.

# Response 22

#### **Reflects Strategic Plan**

No response.

#### Suggested additions

One mission of the NIH DIR should be to perform translational and clinical research on rare and neglected diseases on which the DIR investigators have specific and unique insights and resources not found in the extramural research community and/or synergizes with the extramural research efforts.

#### Suggested deletions

No response.

# Response 23

#### **Reflects Strategic Plan**

The new definition comes across as you dropping any research or efforts into solutions for people's disabilities. Say, a veteran with an amputated leg, no longer deserves research by NIH to address the problem of artificial limbs more integrated into the body of the person.

A person with a disability due to memory lapses no longer deserves efforts by NIH about how to eliminate such memory lapses or reduce their occurrences.

I can add more examples, but I hope you get the idea.

Basically, I think your dropping of "reducing disability" looks like a gigantic middle finger to disabled people who were trusting NIH to be on their side to address the problems their disability is causing them.

#### Suggested additions

To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to enhance health, lengthen life, and reduce illness and disability.

#### Suggested deletions

None

#### Response 24

#### **Reflects Strategic Plan**

Yes!!! It is high time that NIH does away with its ableist mission statement.

#### Suggested additions

None. The proposal is perfect.

#### Suggested deletions

None. The proposal is perfect.

#### Response 25

#### **Reflects Strategic Plan**

No response.

#### Suggested additions

The words "lengthen life" should be added back to be maintained in the proposed mission statement. Alternatively, the word "prevent" could be removed. The proposed mission statement continues to read as ableist biased, as removing "lengthen life" while maintaining

the strong language of "prevent" (one wonders at what length...as exteme measures like euthanasia could be interpreted as "preventing" illness) places overemphasis on curtailing illness, without maintaining a statement more in support of a fundamental value of life in the face of illness/diability.

# Suggested deletions

No response.

# Response 26

#### **Reflects Strategic Plan**

I would end the proposed revised mission statement as "to promote health for all people."

# Suggested additions

In my view, DEI objectives are important, but in this mission statement our priority needs to be continued bipartisan support for our science. DEI objectives do not belong in our fundamental mission statement.

#### Suggested deletions

I would end the proposed revised mission statement as "to promote health for all people."

Promoting health already includes reducing illness and physical stresses.

# Response 27

#### **Reflects Strategic Plan**

I understand why "prevent disability" was removed, but now the mission statement has no reference to disability or the needs of people with disabilities at all, and that feels misaligned from the Strategic Plan.

#### Suggested additions

Something to the effect of, "minimize/mitigate the negative effects of disability on individuals," or "support the health of people with disabilities." Current statement feels like erasure.

Alternatively, language regarding reducing disparities between marginalized groups (which encompasses people w/disabilities) would be appropriate.

#### Suggested deletions

"Optimize" feels like it's in the same family as "remov[ing]...disability." I understand in the statement the verb is targeting the word "health," and we're not optimizing people, but I feel that the health [of people] is implied in the statement. The word choice suggests that there is an "optimal" health for all people and thus people w/disabilities are sub-optimal. But "optimal" health is based on sociocultural norms and the perspective making the determination: "Optimal" health for an employer might be someone who is physically healthy while de-prioritizing mental health (and in some cases, preferring poorer mental health to keep people compliant). "Optimal" health for an individual might be more focused on social and community relationships and the physical fitness needed to enjoy those relationships.

In my opinion, "enhance" was fine.

# Response 28

### **Reflects Strategic Plan**

No response.

#### Suggested additions

Rather than employing the word choice of fixing, or removing disability, NIH could consider the use of the words "including disability." It is a Healthy People 2030 priority that people with disabilities receive the same health services as their able-bodied counterparts do. How are we going do this if we don't include people with disabilities in either quantitative measures or qualitative studies?

#### Suggested deletions

No response.

# Response 29

#### **Reflects Strategic Plan**

I don't know. The new mission statement is better than the current one, as it is more action and results-oriented and less passive. I'm not sure it better reflects the objectives in the strategic plan; however, in my opinion the objectives in the strategic plan were poorly aligned with the mission statement and should be revamped. The organization should be held more accountable for results.

#### Suggested additions

No response.

#### Suggested deletions

No response.

#### Response 30

#### **Reflects Strategic Plan**

I like the original mission statement, which is more specifically targeted to reducing disability. The new language us too vague.

#### Suggested additions

Leave it as it is in old mission statement.

#### Suggested deletions

Keep old mission statement; new one is too vague.

# Response 31

#### **Reflects Strategic Plan**

It does not. This mission statement implies that there is optimal health. This is really marginalizing. Similarly, the statement that we attempt to reduce illness only applies to those who have a condition that is treatable. Many treatments are meant to ameliorate symptoms, but not treat the cause (such as pain research). In this case, the aim is to enhance quality of life, not treat the "illness."

#### Suggested additions

NIH's mission is to seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to lengthen life and enhance quality of life.

#### Suggested deletions

I really don't like the term optimize in the proposed mission statement. To me, this is an overpromise to those with serious illness, including terminal cancer. Optimize means to make the best or most effective use of a situation. For current patients, this is an overpromise—they are participating in trials for future patients. It also implies for people with disabilities that there is some level of optimal health.

# Response 32

#### **Reflects Strategic Plan**

No response.

#### Suggested additions

To discover and impart knowledge about the science associated with living systems in response to disease to alleviate the behavioral and physical impact on human function for all people.

#### Suggested deletions

No response.

# Response 33

#### **Reflects Strategic Plan**

I feel that the proposed revised mission statement better reflects the goals of the NIH and is more inclusive of those with disabilities, without using harmful language that can be seen as dehumanizing toward this group.

#### Suggested additions

An additional suggestion would be: "to apply that knowledge to optimize health, ability, and to prevent or reduce illness for all people."

The idea of optimizing ability can mean providing opportunities for those with disabilities more tools to function in society, as well as providing society more ways to be inclusive of people with a variety of needs.

n/a

# Response 34

# **Reflects Strategic Plan**

I would like to add to the mission statement the following, which is not included from my reading. Empowering lives challenged by chronic illness through comprehensive, personalized care that addresses medical, emotional, and social dimensions, fostering well-being and resilience.

#### Suggested additions

Empowering lives challenged by chronic illness through comprehensive, personalized care that addresses medical, emotional, and social dimensions, fostering well-being and resilience are those diseases that are incurable, new, or vary over time in managing the lives of peoples in all settings.

#### Suggested deletions

I really think that it is important to address chronic illness as the population ages in place.

# Response 35

# **Reflects Strategic Plan**

I personally think the mission statement is succinct and to the point. Very good and does not require revision.

#### Suggested additions

None.

#### Suggested deletions

None.

# Response 36

#### **Reflects Strategic Plan**

No response.

#### Suggested additions

No response.

#### Suggested deletions

Remove the word "to" in front of optimize to create an ellipsis. The second "to" is redundant. Remove the word "optimize," as it usually refers to most effective use of something, and replace it with something else, possibly "enhance," as was used before. Remove the word "prevent," as it is redundant because reducing illness for all people includes preventing illness.

# Response 37

### **Reflects Strategic Plan**

Shorten the proposed revised mission statement as follows:

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

#### Suggested additions

No response.

#### Suggested deletions

"to prevent OR reduce illness" is weird and unnecessary. "to prevent AND reduce illness" is better but still unnecessary!

"to optimize health for all people" is perfect!

# Response 38

#### **Reflects Strategic Plan**

Yes, it does, but after reading the 35 Bold Predictions included in the Strategic Plan, the mission statement sounds a little clunky and outdated.

#### Suggested additions

N/A

#### Suggested deletions

Remove "and prevent or reduce illness," so the mission statement reads: To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to optimize health for all people.

# Response 39

#### **Reflects Strategic Plan**

Yes, the proposed new mission statement is a much more accurate reflection of the goals and objectives of the NIH strategic plan—as we as an institution are seeking to optimize health for ALL people. A sincere thank you to whomever came forward with this issue and to those who listened and are helping to create the solution!

As someone with a disability who works at NIH and has wanted to be able to fully embrace the entire NIH mission statement, it is exceptional that the proposed new NIH mission statement no longer contains language that is indirectly threatening towards those like me with a disability and our existence (i.e., the old NIH mission statement came across as a stark warning of the historically very real potential that the NIH could aim towards a future application of reducing chronic illness and disability, literally, by reducing the living number of disabled and chronically ill—using innovative scientific knowledge and methods with accompanying NIH mission statement backed medical rationalization—in order to enhance the health and life of those currently healthy individuals who are without chronic illness or disability).

### Suggested additions

Specifically, the language of the proposed mission statement needs to state "...and to apply that knowledge to optimize health for all people..." to really correct the error in the old mission statement. For instance:

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

Basically, the mission statement should directly indicate that NIH's overarching aim is the optimization of health for ALL people, throughout their ENTIRE lives regardless of their current or prior health levels.

#### Suggested deletions

No response.

# Response 40

#### **Reflects Strategic Plan**

No response.

#### Suggested additions

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

Mental health is too often stigmatized and not considered an illness that needs to be treated. It therefore should be included within the NIH mission statement. especially since we have Institutes (NIMH) and addiction programs (HEAL) that are dealing with mental health concerns.

#### Suggested deletions

No response.

#### Response 41

#### **Reflects Strategic Plan**

Seems to match up pretty well.

#### Suggested additions

I think using the phrase "enhance health, lengthen life, and reduce illness for all people" works well and is not as cumbersome to read/say aloud as the proposed phrase that has multiple conjunctions. The change to "...for all people" also adds in the desired inclusivity.

Removing "...reduce... disability" is likewise an inclusive change that I agree with. You could adjust the term to infirmity, such that it reads as "enhance health, lengthen life, and reduce illness and infirmity for all people," but again, this becomes somewhat cumbersome to read.

The term optimize does not sound appropriate in this setting. It simply sounds detached and somewhat lacking in compassion. From a denotation standpoint, the mechanics underlying human health will vary person-to-person such that no one treatment/prevention modality will be all-encompassing for everybody. Hence, it is not really possible to "optimize health... for all people." You create multiple modalities and pair them up person-to-person (often with much trial-and-error in between) to get the best efficacy. That is not optimized.

Furthermore, what is considered "optimized health" is going to vary person-to-person. When a patient with chronic disease comes into clinic, they will have their own personal goals when it comes to treatment. Some will want to take the most intensive course possible to extend the time they have left, while others will favor less intensive treatment with fewer adverse effects—even if it means they will likely pass sooner.

You could take the standpoint that you are "optimizing health" per the needs of each person, but at that point I believe the term "enhance" simply works better and does not have the same impersonal connotation about it.

I would also drop the term "prevent" and simply keep as "reduce illness for all people." The reduction of illness has multiple components—two of which are the reduction of disease incidence/prevalence and the severity of disease. Both are already implicit. To say that the mission is to "prevent or reduce illness" is just redundant.

# Response 42

# **Reflects Strategic Plan**

I like the move to make the mission statement more grammatically simple. The proposed statement sounds more actionable.

#### Suggested additions

I'm unclear why "and disability" was struck from the mission statement. It seems NIH research would still be meant to find ways to ease the healthcare burden of disability, which (colloquially) is distinct from an illness or disease.

#### Suggested deletions

"Optimize" health feels like a strange, technical choice of word when the original "enhance" seems suitable.

# Response 43

#### **Reflects Strategic Plan**

No response.

#### Suggested additions

Please add "prevention or minimization of medical disability" into the verbiage.

Webster's first description of disability is: "a physical, mental, cognitive, or developmental condition that impairs, interferes with, or limits a person's ability to engage in certain tasks or actions or participate in typical daily activities and interactions." By definition, this is

clearly an area of concern for the National Institutes of Health and should be a goal to prevent or minimize the impact of such conditions.

Erasure of verbiage relating to disability steers focus away from aiding those who are or will be disabled. We all know and love people who have various disabilities. Please keep this as a central part of the mission of the NIH.

#### Suggested deletions

No response.

# Response 44

#### **Reflects Strategic Plan**

No response.

#### Suggested additions

Why not "... apply that knowledge to optimize health and promote well-being for all people?" Promoting well-being is strengths-based and includes prevention and treatment without reducing people's disabilities, chronic conditions, and mental health to an "illness" (i.e., implying that there's necessarily something wrong with them). Neurodivergence is not an illness. Being deaf isn't an illness. Mental health conditions related to the experience of trauma are not illnesses (they are adaptive responses to extreme conditions). Many people experience health problems not because of illness but because the world is not set up for them to be healthy—reducing these health concerns to "illnesses" implies that the causal factors lie with the individuals and/or their bodies, rather than with the environment and social structure that has created conditions in which they can't be well.

#### Suggested deletions

"Reduce illness." This language reduces people's disabilities, chronic conditions, and mental health to "illnesses" (i.e., implying that there's necessarily something wrong with them). Neurodivergence is not an illness. Being deaf isn't an illness. Mental health conditions related to the experience of trauma are not illnesses (they are adaptive responses to extreme conditions). Many people experience health problems not because of illness necessarily, but because the world is not set up for them to be healthy—reducing these health concerns to "illnesses" implies that the causal factors lie with the individuals and/or their bodies, rather than with the environment and social structure that has created conditions in which they can't be well.

# Response 45

#### **Reflects Strategic Plan**

The old and new mission statement reflects the goals and objectives as outlined in the NIH-Wide Strategic Plan for Fiscal Years 2021–2025.

#### Suggested additions

I think the new statement should read: "To search for the truth about the nature and behavior of living systems and to apply that knowledge to improve health outcomes by preventing and/or reducing illness for all individuals."

This statement better represents that we (the scientific community) are striving to better understand the science of our world without bias and applying that new-found knowledge to better improve health outcomes.

### Suggested deletions

Please remove "optimize" from the new mission statement. "Optimize" implies that people are flawed and that suboptimal treatments/therapies will be applied in search of the best solution. Instead, using the term "to improve health outcomes" implies that the NIH scientific community is striving for the best solution.

# Response 46

#### **Reflects Strategic Plan**

No response.

#### Suggested additions

I suggest adding back "and disability" next to "reduce illness." Not all disability is caused by illness. Also, without those words, the proposed statement seems to exclude research looking at ways to partially reverse certain disabilities.

#### Suggested deletions

No response.

# Response 47

#### **Reflects Strategic Plan**

It does. But, it is missing a "quality of life" reference. Length of life should not come at the price of quality. Mental health should be equally reflected as physical health.

#### Suggested additions

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

#### Suggested deletions

Nothing to remove. Please consider adding "quality of life" to the statement.

# Response 48

#### **Reflects Strategic Plan**

I do not think the proposed new mission statement reflects the goals and objectives as outlined in the NIH-Wide Strategic Plan for Fiscal Years 2021–2025. Disability is real, and for many of us, this is a burden. While some people with disabilities believe that using the term perpetuates ableist attitudes, many with disabilities—and their families—understand that they are not fully able-bodied. Disabilities come at a range of degrees.

The NIH's first mistake was removing the term "burdens" from the NIH mission statement— "reduce the burdens of illness and disability." This was done because a person who was deaf didn't see how his deafness was a burden on society. As a person with a family member with a disability, I found his comment naive and insulting. He may think that his own deafness isn't a burden, but that may be because society has reduced his burden by mandating closed captioning, assigning sign-language interpreters, improving access to public schools, etc. My very good friend's parents are both deaf, and their deafness was an incredible burden on her growing up. Modern technologies slowly reduced those burdens.

So, the NIH was left with the grammatically awkward "reduce illness and disability." One can reduce the rate of illness, the severity of illness, the incidence of illness, but not "reduce illness" itself. As such, "reduce disability" sounds alarming, as if we are trying to eliminate people.

# Suggested additions

There was nothing wrong with "reduce the burdens of illness and disability." That's what the NIH does every day in the pursuit of treatments. Treatments reduce the burden or severity of a disease or disability. By reducing burdens, we enable those with illness or disability to more fully participate in society. Closed captioning reduces burdens. Audio cues reduce burdens. Better wheelchairs reduce burdens. Pain medications reduce burdens. And so on and so on.

If NIH revises its mission again to simply state "to optimize health and prevent or reduce illness for all people," how will this imply that the NIH is helping to reduce burdens and enhance engagement for those with severe disabilities? Consider new powered wheelchairs that can get wet, enabling a paraplegic child to enter a waterpark. The wheelchair didn't optimize her health. The wheelchair didn't prevent illness. The wheelchair didn't reduce illness. The wheelchair provided access to fun otherwise denied because of the burden of not being able to enter a waterpark in a powered wheelchair for fear of electrocution.

# Suggested deletions

How soon will it be until someone questions your revised mission statement, wondering where they fit in? The proposed new mission statement excludes a large section of the population who aren't ill, per se (having no legs is not an illness), but rather have a disability that prevents them from fully engaging with others.

I had predicted the current predicament when the mission statement was changed in 2013. I raised this with NIH leadership to no avail. And so, here we are ready to make the flawed mission statement even worse.

# Response 49

# **Reflects Strategic Plan**

The proposed statement is more correct and concise than the original. I really like it! Well done.

# Suggested additions

Please consider adding the word "humanely." "To humanely seek fundamental knowledge...." This would give a sense of ownership and relief to animal caretakers and researchers. This is a topic of great concern in the average population regarding Government research that I understand is clarified in regulations, certifications, licensing of facilities, etc. But it could provide re-assurance and awareness of the Government's commitment to humane processes if in the mission statement.

No response.

# Response 50

# **Reflects Strategic Plan**

I like the new statement. It's simple and direct.

### Suggested additions

No response.

#### Suggested deletions

No response.

# Response 51

# **Reflects Strategic Plan**

The statement is good but providing a suggestion below.

#### Suggested additions

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 to improve the overall well-being of humanity.

#### Suggested deletions

No response.

# Response 52

#### **Reflects Strategic Plan**

No response.

#### Suggested additions

"Optimize health and prevent or reduce illness" leaves out a key area of NIH's mission with respect to preventing/reducing a variety of harms that can result from injury/accident or failure to address an illness in a timely fashion or emotional or financial harm that results from health care processes. How about including the word "harm"? e.g., "To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to optimize health, prevent or reduce illness, and prevent or reduce harm for all people."

#### Suggested deletions

No response.

# Response 53

#### **Reflects Strategic Plan**

I agree that the newly proposed language is better; however, I do think that maybe the NIH should consider evaluation as part of its mission statement as well. As in, "and to frequently evaluate the impact of its decisions on all people," or something similar.

#### Suggested additions

As stated above, I think evaluation of the impact the NIH has should be in its mission statement. I realize you want to keep it short, but evaluating the actual impacts, as best we can, is key. Doing the action listed in the statement is a start, but without identifying the positive, neutral and negative or intended and unintended consequences of our actions, we may not be accomplishing our mission.

I also feel that maybe some language about not sacrificing the health of its employees, intramural or extramural researchers, or study participants in pursuit of the mission is key. Maybe something about accountability to our goals, our people, and the people we impact.

#### Suggested deletions

n/a

# Response 54

#### **Reflects Strategic Plan**

Yes.

#### Suggested additions

None. Revision is great. Thank you for removing the ableist language.

#### Suggested deletions

None. Good as suggested in revision.

# Response 55

#### **Reflects Strategic Plan**

I am not sure why lengthen life was removed. Lengthening life does seem consistent with the strategic plan and it is an important part of our work.

#### Suggested additions

Is it necessary to use the word illness? There are a number of ways that health is worsened that are not considered illness. Perhaps disability is not the right word, but having quality of life is not just being free of illness.

#### Suggested deletions

No response.

# Response 56

# **Reflects Strategic Plan**

I think NIH needs to focus on a holistic approach to life. NIH must introduce counseling, shamanism therapy, and yoga to enhance life, for this a holistic concept is needed.

"To seek holistic 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."

#### Suggested additions

"To seek holistic 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."

#### Suggested deletions

No response.

# Response 57

#### **Reflects Strategic Plan**

New Proposed 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."

This sentence may not be a run-on sentence, but it is not clear and should be concise with an easy to follow point. It doesn't reflect diction of a national institution with the highest form of scientific credibility and perspective on illness.

#### Suggested additions

#### My Revised New Statement:

"To discover and apply fundamental knowledge of human health in all environments for the promotion of health optimization, disease prevention, and illness reduction for all people."

I think it's important to separate disease prevention and illness reduction for all people. Prevention can be something as simple but highly effective as safety nets or mosquito spray, while disease reduction can be something as complex and uncertain as chemotherapy or radiation for cancer cells. I put "all" twice because I wanted to emphasize the importance of the mission to be inclusive, diversity-driven, and open-ended.

#### Suggested deletions

#### Unrevised New 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."

#### My Revised New Statement:

"To discover and apply fundamental knowledge of human health in all environments for the promotion of health optimization, disease prevention, and illness reduction for all people."

I intentionally replaced "seek" with "discover," rephrased "nature and behavior of living systems" with "human health in all environments," changed "optimize" to "optimization,"

and removed a lot of highly unnecessary and redundant prepositions that create an ambiguous and unconfident tone.

# Response 58

### **Reflects Strategic Plan**

Somewhat reflects the goals and objectives—like the inclusion of language to highlight the translation of discovery research.

#### Suggested additions

The inclusion of disability to the statement "...optimize health and prevent or reduce illness and disability for all people" might better capture the goals of the Strategic Plan. I'm not sure if there was a political reason for removing it from the current mission statement, but it relates to conditions that are not necessarily an illness (disease of period of sickness), but rather a loss of functioning. This is especially important in consideration of an aging population that is not ill but rather infirm.

#### Suggested deletions

Since "nature" in the context of this mission statement refers to life broadly, there isn't a reason to add behavior as a separate category. It should be simplified to "To seek fundamental knowledge about the nature of living systems and to apply that knowledge to optimize health and prevent or reduce illness and for all people."

# Response 59

### **Reflects Strategic Plan**

"Health" should be expanded to incorporate wellbeing. Perhaps change "health" to "wellbeing" or to "whole person health."

From NCCIH: Whole person health involves looking at the whole person—not just separate organs or body systems—and considering multiple factors that promote either health or disease. It means helping and empowering individuals, families, communities, and populations to improve their health in multiple interconnected biological, behavioral, social, and environmental areas. Instead of treating a specific disease, whole person health focuses on restoring health, promoting resilience, and preventing diseases across a lifespan.

#### Suggested additions

optimize whole-person health...

#### Suggested deletions

I think "nature and behavior" are redundant. Since someone's nature is their character, which is exhibited in part by their behavior. It's also not clear why "behavior" is noted and not "cognitive processes," which can also cause illness.

# Response 60

#### **Reflects Strategic Plan**

In general, the proposed mission statement reflects the goals and objectives of the strategic plan. The addition of the phrase "for all people" is helpful in assuring that research missions

include representative samples and that findings will be generalizable. The major gap in the mission statement is that it doesn't mention the need for workforce development to assure the futures of foundational, translational, and clinical research.

### Suggested additions

As noted above, the main gap as compared to the strategic plan is the lack of mention of research workforce development. One could start the statement with "To develop scientists and leaders in biomedical research"; however, that may distract from the other key elements of the mission statement.

# Suggested deletions

The proposed statement could be condensed to read "To seek fundamental knowledge about living systems and apply that knowledge to optimize health for all people."

Fundamental knowledge of living systems may include more than just their nature and behavior (regardless of how those are defined). Deleting these words broadens the statement and also makes it more succinct.

Prevention or reduction in illness or disease is part of optimizing health. On the other hand, some interventions that are aimed at preventing or reducing disease may have their own side effects. The use of such interventions and balancing of their benefits and harms is a clinical judgment and may be needed until treatments are available with fewer adverse effects. Nevertheless, the goal of research should be aimed at improving overall health, functioning, and well-being, rather than illness reduction per se.

# Response 61

### **Reflects Strategic Plan**

No response.

#### Suggested additions

"optimize human health, lengthen life, and prevent or reduce illness"

#### Suggested deletions

No response.

Response 62

#### **Reflects Strategic Plan**

No response.

#### Suggested additions

No response.

#### Suggested deletions

Recommend removing the words "prevent or." 1. The inclusion of these words creates a strangely worded statement that seems overly technical in an attempt to "catch all" the possible examples. 2. Prevention by definition would be a reduction, so you've already said this by saying reduce.

"To seek fundamental knowledge about the nature and behavior of living systems and [to] apply that knowledge to optimize health and reduce illness for all people." You also don't need the "to" between and ... apply that knowledge.

# Response 63

#### **Reflects Strategic Plan**

No response.

#### Suggested additions

Our Mission here at the NIH is to pursue essential recognition about the character and demeanor of Living Systems. The inquiry into this awareness will help to strengthen health, prolong life, decrease illness, and limitations.

#### Suggested deletions

No response.

Response 64

#### **Reflects Strategic Plan**

No response.

#### Suggested additions

No response.

#### Suggested deletions

Too many "to's."

"To seek fundamental knowledge about the nature and behavior of living systems, and apply that knowledge towards optimizing health and preventing or reducing illness for all people."

# Response 65

#### **Reflects Strategic Plan**

The language of the new mission statement does not, by any means, speak to the quality of health or life of individuals and it reflects the NIH as a utilizer of individuals' health, rather than a public institution functioning in service to health.

#### Suggested additions

The language of the new mission statement does not, by any means, speak to the quality of health or life of individuals and it reflects the NIH as a utilizer of individuals' health, rather than a public institution functioning in service to health.

The word "optimize" should be replaced with "enhance."

Enhance is defined by the oxford dictionary as "intensify, increase, or further improve the quality, value, or extent of," whereas optimize is defined as "make the best or most effective use of (a situation, opportunity, or resource)." These definitions are significantly different, and can generate great harm to many individuals. The word "optimize" regards individuals'

health as a resource to be utilized rather than an attribute belonging to individuals that they have authority over. The goal of the NIH should always be to "further improve the quality, value and extent of" (enhance) individuals' health, not to "make the most effective use of" (optimize) individuals' health. The NIH should not assume authority over individuals' health. Correctly interpreted, this change of wording instructs the NIH to utilize individuals' health rather than improve it and this would be detrimental for many as it no longer prioritizes the individuals' best interest, but rather what the NIH deems as the best interest, which is unclear.

"Lengthen life" should be added to the mission statement.

Health is defined as "a person's mental or physical condition." This definition does not account for the length of life, therefore "lengthen life" should be explicitly stated in the mission statement.

#### Suggested deletions

"for all people" should be removed, or replaced with "for the citizens and residents of the United States of America." "For all people" is too vague and does not demonstrate the proper limits of the NIH. The National Institutes of Health should not assign itself the duty of "optimizing" or even "enhancing" the health of citizens and residents of other countries. This is an over-extension of its resources and authority.

# Response 66

# **Reflects Strategic Plan**

No response.

#### Suggested additions

I would encourage you to consider expanding the statement in a way that explicitly commits the NIH to pursuing its mission with diversity, equity, and inclusion at the forefront.

#### Consider, perhaps:

"To seek fundamental knowledge about the nature and behavior of living systems and apply that knowledge towards equitably optimizing health and preventing or reducing suffering and illness for all people."

#### Suggested deletions

I am glad to see the ableist language being removed from the statement.

# Response 67

#### **Reflects Strategic Plan**

I think that the revision is excellent! I love that NIH is moving to be less ableist by removing this kind of language.

#### Suggested additions

No response.

No response.

# Response 68

# **Reflects Strategic Plan**

The proposed mission statement is inclusive and a good step forward to the NIH.

### Suggested additions

Potentially could include "wellness" so it reads "...to optimize health and wellness...." Adding wellness may expand beyond the traditional western-style focus on bodily health.

#### Suggested deletions

No response.

Response 69

# **Reflects Strategic Plan**

No response.

#### Suggested additions

Add "lengthen life" back into the statement. With the challenges to the life span faced by many Americans living in poverty, facing disparate treatment in healthcare, and the substance use/opioid challenges, lengthening life needs to be an important and stated part of the goal.

#### Suggested deletions

"Reduce" should be removed. Reduction is part of the process, but to make it a goal is accepting less than what the people of the United States deserve for all that they contribute to the Treasury that funds NIH research. The goal is to prevent illness and reducing it is just part of the journey to wellness not a legitimate goal.

# Response 70

#### **Reflects Strategic Plan**

Yes, this reflects the goals of the strategic plan.

#### Suggested additions

I would suggest adding the following three words, "and its consequences" in the following position of the statement: "...and prevent or reduce illness and its consequences for all people."

The reasoning for this addition includes the need to emphasize that there are long term issues that many people must deal with that are the result of a short-term disease which may lead to long-lasting persistent organ damage or injuries. Thus, it may not be the illness itself that is important to the health and well-being of the individual, but the accumulation of the consequences of illnesses, exposures, and injuries. This concept is important for understanding the value of life-course research and aging research, among others.

I would not remove any language.

# Response 71

# **Reflects Strategic Plan**

I agree that the proposed revised mission statement is an improvement in keeping with the Strategic Plan.

#### Suggested additions

No response.

# Suggested deletions

As a health communications professional, I suggest editing the new mission statement as follows: "To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to optimize health for all people." The phrase "optimize health" can be read to encompass both prevention and reduction of illness.

# Response 72

# **Reflects Strategic Plan**

I feel the new language erases disability by folding it in with improving health for all people.

# Suggested additions

The old language was fine.

#### Suggested deletions

No response.

# Response 73

#### **Reflects Strategic Plan**

Yes, but it could be even more concise without losing meaning.

#### Suggested additions

N/A

#### Suggested deletions

Remove "and prevent or reduce illness" because "optimizing health" already includes preventing and reducing illness.

# Response 74

#### **Reflects Strategic Plan**

Yes, but missing stronger emphasis on equality of access to healthcare as a fundamental human right.

# Suggested additions

The NIH's mission encompasses the preceding statement and recognizes that equal access to healthcare is a fundamental human right.

# Suggested deletions

N/A

# Response 75

#### **Reflects Strategic Plan**

Can you please include coming up with research, treatments, and clinical trials for complex chronic illnesses like Myalgic Encephalomyelitis (ME/CFS), Long Covid, and Postural Orthostatic Tachycardia Syndrome (POTS)?

#### Suggested additions

ME/CFS.

#### Suggested deletions

No response.

# Response 76

#### **Reflects Strategic Plan**

This is much improved.

#### Suggested additions

However, it is still missing a key component regarding access. Perhaps, "optimize health, increase access to healthcare and prevent or reduce illness for all people."

#### Suggested deletions

No response.

# Response 77

#### **Reflects Strategic Plan**

No, it doesn't reflect your goals and objectives because you have eliminated those who are disabled. You have not abandoned us, I'm sure. But the new mission statement either excludes us and defines us as ill. I am missing an arm. I am not ill. I am disabled. You are not supporting disability inclusion by eliminating us. There is nothing "ableist" is acknowledging that I am missing an arm, that I am disabled, and that I benefit from assistive technologies that reduce this burden of having only one arm.

#### Suggested additions

Why not say "to optimize health and prevent or reduce the burden of disability and illness." Isn't that the core of what NIH does, create therapies and technologies that improve lives? Those of us who are disabled and think they aren't disabled think that way because others have strived to reduced their burden of disability so that they can interact more easily with the greater society: go to movies, drive a car, etc. Moreover, my family also benefits from my prosthetic arm because I can engage more easily with my children.

Or, how about using the term "health challenges"? "Our mission is to conduct groundbreaking research, foster interdisciplinary collaboration, and drive innovation to prevent, diagnose, and treat a diverse spectrum of diseases and health challenges."

Or go with something bland and unoffensive to no one, if that's the goal: "The NIH advances understanding of life systems and their applications to improve health, longevity, and well-being."

# Suggested deletions

If you plan to leave out the disabled, then why not leave out the ill? What is illness, anyway? Is it not ableist to assume that those with illness are "are flawed" and need to be "fixed"?

Leave it at "To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to optimize health."

# Response 78

#### **Reflects Strategic Plan**

No response.

#### Suggested additions

Could say promote accessibility instead of reduce disability.

#### Suggested deletions

No response.

#### Response 79

#### **Reflects Strategic Plan**

As always, the NIH mission statement reflects its goals and objective, including the recent new one.

#### Suggested additions

Gaining insight into the nature and behavior of living system in order to apply that knowledge for better health management, effective disease treatment, alleviating pain symptoms.

Gain insight—accurate and indepth understanding Apply knowledge—utilize and implement knowledge usefully Better health management—providing the best and latest treatment regimen Effective disease treatment—positive outcomes in disease control and eradication Alleviating pain symptoms—lessening the discomfort and pain associated with illness for better quality of life

Seeking—trying to find out (is not assertive)

Fundamental knowledge—basic findings (NIH was founded more than 12 decades ago in 1880s, yet the basic findings)

Optimize health—the best or most effective (does not imply higher quality as meant by better)

Prevent or reduce—interrupt something from occurring takes precedence over prevention

# Response 80

# **Reflects Strategic Plan**

I support this change, and as an employee of the NIH I applaud the agency for its diversity, equity, and inclusion efforts.

# Suggested additions

N/A

# Suggested deletions

N/A

# Response 81

# **Reflects Strategic Plan**

I think the current mission statement sounds like the NIH focuses only on illness, not all the challenges the patients and caregivers face due to illness, such as financial toxicity.

#### Suggested additions

I suggest "to apply that knowledge to optimize health, prevent illness, and reduce suffering from illness for all people." I think "reduce suffering from illness" would cover all the challenges patients and caregivers face due to illness, not only illness.

#### Suggested deletions

No response.

#### Response 82

#### **Reflects Strategic Plan**

I think the mission statement looks good. One comment: training and education aren't explicitly mentioned. In my opinion, it would be beneficial for NIH to continue supporting training and education, and perhaps even prioritize it more.

#### Suggested additions

Add the following bullet point:

To advance and prioritize training and education programs, recognizing the rapid pace of emerging measurement technologies and data analysis techniques. It is essential expand the workforce equipped with latest knowledge, skills, and ethical standards and offer established biomedical scientists a way to keep current. This ensures a robust, dynamic, and informed community capable of navigating and harnessing the rapid advancements in medicine and health.

#### Suggested deletions

No response.

# Response 83

#### **Reflects Strategic Plan**

Yes, it does. The proposed mission statement is more active and succinct.

#### Suggested additions

No response.

#### Suggested deletions

No response.

# Response 84

#### **Reflects Strategic Plan**

The proposed new mission statement is a good start. I suggest adding "AND ITS IMPACT" to the statement, such that it reads: "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 and its impact for all people."

#### Suggested additions

I am a clinician who is in active clinical practice and as a leader in the diversity, equity, inclusion, and accessibility space focusing on disabilities. In my experience, many illnesses are chronic and will always stay with a patient. It's more important to manage the illness and mitigate its impact on daily living so that the patient can function without barriers where possible. That may involve treating the illness to maintain function. It may also involve simply removing barriers so that the effect of the illness is minimized. This is the social model of disability (and not the medical model).

#### Suggested deletions

No need to remove any word from the proposed new mission statement. Just add "and its impact," such that it reads "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 and its impact for all people." You may wordsmith it to flow better, but the main idea is to not just prevent/reduce illness but ALSO THE IMPACT of illness.

# Response 85

#### **Reflects Strategic Plan**

No response.

#### Suggested additions

I strongly suggest "promote the application of that knowledge" instead of "to apply" knowledge. Our mission is research. Discovery. Not application of what we discover. The impact of our work is entirely dependent upon others applying that knowledge! The pandemic was a brilliant example of that. Our research contributed to discovery of the vaccine, and our implementation science research helped us "get shots in arms." NIHsupported health communications research from HIV/AIDS helped us combat misinformation and disinformation—and those are just a few examples of prevention science in action from bench to community. We need pharmaceutical companies to produce vaccine, practitioners, and clinical practice guidelines to safely and effectively administer treatments across age ranges and health risk groups. We need policy makers to help address a range of public health concerns at the population level, and payors—public and private—to efficiently cover costs. It would be WONDERFUL if we could do a better job at promoting the uptake and use of the excellent science that our investigators generate, much of which contributes to an evidence base that can inform whatever it is we say at the end of our mission statement sentence! We don't do nearly enough to promote the impact of what we already know and what we will learn in the future. That is another meaning of the word "promote," which in that way also carries an aspirational meaning.

# Suggested deletions

No response.

# Response 86

### **Reflects Strategic Plan**

No response.

#### Suggested additions

I would suggest a slight alteration to the statement as follows:

"To seek fundamental knowledge and understanding of the nature and behavior of living systems and to utilize that knowledge to optimize health and identify, reduce, and prevent illness for all people."

I think it is important to emphasize that we are both gaining knowledge and understanding what we have learned in a practical manner that allows us to fully utilize that knowledge.

Also, I would emphasis that some of our work here is related both to the discovery of new illnesses/disorders and the early detection of known ailments, such as many forms of cancer.

#### Suggested deletions

No response.

# Response 87

#### **Reflects Strategic Plan**

I like many aspects of the updated mission statement, but I worry that it misses an element that is becoming increasingly important for American society—disseminating trustworthy, non partisan information to the public.

### Suggested additions

I would add a second sentence:

"To be a non-partisan purveyor of evidence-based information about biomedical science and its relationship to health to the public"

# Suggested deletions

No response.

# Response 88

# **Reflects Strategic Plan**

The mission statement is fine the way it is. The proposed change is obviously an attempt to pander to one or more of the narrowly-focused special interest groups that have unfortunately infiltrated this and many (if not most or all) government entities.

# Suggested additions

No response.

# Suggested deletions

No response.

# Response 89

# **Reflects Strategic Plan**

Support proposed revision.

#### Suggested additions

No response.

#### Suggested deletions

No response.

#### Response 90

#### **Reflects Strategic Plan**

The proposed new mission statement is better than the existing statement. There is room to consider further revisions. (See below)

# Suggested additions

"To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to optimize health and reduce preventable illness, or reduce the impact of illness and remove factors that lead to the experience of illness for all people."

#### Suggested deletions

The only word I would recommend removing is "prevent illness." Some illnesses are genetic and the only way to prevent it would be to terminate the individual, which is not the goal we want to achieve. The spirit of NIH sponsored research is to show that research should focus on all of the following: (1) optimize health, (2) reduce preventable illness, (3) reduce the impact of illness, and (4) remove factors that contribute to the experience of illness.

# Response 91

# **Reflects Strategic Plan**

I do not believe the mission statement addresses the need to better understand aspects of mental illness that do contribute to adverse risks to physical health and poorer quality of life.

#### Suggested additions

Specific language that might be added include

Understanding of all aspects of health, including mental, physical, and cognitive wellbeing, to optimize health and quality of life.

# Suggested deletions

No response.

# Response 92

#### **Reflects Strategic Plan**

The additional verbiage below would add another topic to the strategic plan in embracing non destructive testing like Computer Simulation Models.

#### Suggested additions

"To seek fundamental knowledge about the nature and behavior of living systems in a non destructive manner and to apply that knowledge to optimize health and prevent or reduce illness for all people, and to cease the cruel and unethical practice of testing on animals, innocent sentient beings that have no choice in the matter."

#### Suggested deletions

n/a

Response 93

#### **Reflects Strategic Plan**

No response.

#### Suggested additions

The mission of the NIH is to offer hope for preventative, curative or palliative care to humans across the globe suffering from poor mental or physical health. Through scientific endeavors to understand, describe and transform health and disease from basic proteins of the genome to the complexities of epidemiology, community and environment that pressure maladaptation of the human condition.

#### Suggested deletions

No response.

# Response 94

# **Reflects Strategic Plan**

The proposed new mission statement reads well. It is clear, direct, and inclusive. No suggestions.

#### Suggested additions

None

# Suggested deletions

None

# Response 95

# **Reflects Strategic Plan**

The proposed statement, while reflecting the goals, have terms that are ambiguous. My suggestion avoid those terms and may:

To seek "structural and functional" knowledge about the "biology" and behavior of living systems and to apply that knowledge to "maintain" health and prevent or "treat" illness for all people.

# Suggested additions

"Structural and functional"

Biomedical research seeks to understand the structure and function; while that could be aggregated in the term fundamental, that term could have an unintended negative significance outside science. Therefore, the use of "structural and functional" avoids confusion and better define the object of biomedical research.

"Maintain"

The definition of health by WHO is a "a state of complete physical, mental, and social wellbeing and not merely the absence of disease or infirmity." Therefore, it seems counterintuitive that something that is complete could be optimized.

If we accept this definition of health, the appropriate term for the NIH statement would be "maintain," rather than optimize.

"Treat"

The statement should encompass both the individual and the public. The term "reduce" may not correctly capture the intent for both situations. To reduce the burden of disease or to reduce diseases (infectious, cardiovascular, metabolic, cancer) as a public health matter, is an objective to be pursued. At the individual level, the term reduce may represent a quantitative improvement of a diseases rather than a cure.

The term "treat" would be applicable to both situations: the person and the public health (or disease).

#### Suggested deletions

See above: "fundamental" "nature" "optimize" "reduce"

# Response 96

### **Reflects Strategic Plan**

I think the new mission statement is worse than the old one. I read it and say "what." Then I re-read it. It should be in plain language so that even someone with a third grade education can understand. The current mission statement nor the proposed does not appeal to the masses. Who's coming up with this!

#### Suggested additions

Our mission is to uncover the many different reasons why the human body gets sick. To discover the root cause of diseases that come from the 5 agents viruses, bacteria, fungi, protozoa, and helminths (worms) and how they transfer to humans. At NIH we determined to develop treatments and cures so that every human being can live a delightful life.

#### Suggested deletions

All of it needs to be removed. It reads like a "know it all," a non compassionate person wrote it. Again it doesn't speak to the majority of people. It needs to be in plain language. Some that doesn't have a doctoral degree needs to read it easily.

# Response 97

#### **Reflects Strategic Plan**

No response.

#### Suggested additions

No response.

#### Suggested deletions

I suggest the following updates for a more direct statement and enforcing plain language:

- (1) remove "about the" and replace it with "on""
- (2) removing "and to" and replacing it with just "and"
- (3) switch the word "and" to "to"

Which will then read:

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

#### Response 98

#### **Reflects Strategic Plan**

The proposed mission statement wording gives an inclusivity to all people.

#### Suggested additions

A suggestion to include on the proposed mission statement should somehow state inclusivity devoid of ethnicity somewhere.

Going forward, if the enclosed suggestions are included in the mission statement, then the mission statement should be satisfactory.

## Response 99

## **Reflects Strategic Plan**

No response.

### Suggested additions

1. Mission and goals:

NIH's mission 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

#### PROPOSED CHANGE:

NIH's mission is to seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to optimize health, to treat and prevent or reduce illness for all people.

Justification: Emphasizing treatment

#### 2. The goals of the agency are:

To develop, maintain, and renew scientific human and physical resources that will ensure the Nation's capability to prevent disease;

#### CHANGE TO:

To develop, maintain, and renew scientific human and physical resources including underrepresented groups that will ensure the Nation's capability to prevent and treat disease.

Justification: Emphasizing NIH's commitment to inclusiveness and development of capabilities for treatment

### Suggested deletions

No response.

## Response 100

### **Reflects Strategic Plan**

I do think it reflects the goals and objectives outlined in the strategic plan.

It is interesting that the strategic plan focuses a lot on improving the function of humans at the level of the cell or specific organ, but says very little about whole person function. This appears out of step with what the people who are the subjects in our study would prioritize. We need both kinds of work—that work that looks at the function of cells and organs and the work that looks at the function of the person.

It's important to recognize the need to address functional impairment while not pathologizing disability. Some options might include:

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

OR

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

### Suggested deletions

No response.

## Response 101

### **Reflects Strategic Plan**

I suspect most people will only fill out this RFI if they have suggestions. I just want to say I think this is a great and well-informed change. Kudos!

#### Suggested additions

No response.

### Suggested deletions

No response.

## Response 102

### **Reflects Strategic Plan**

I very much appreciate the shift away from "to reduce illness and disability" and toward "to optimize health and prevent or reduce illness for all people." This new language removes the stigma and negative association with disability as something negative to be eliminated, while still expressing a desire to optimize health and reduce illness for all.

#### Suggested additions

No response.

### Suggested deletions

No response.

### Response 103

### **Reflects Strategic Plan**

I support this New language: "to optimize health and prevent or reduce illness for all people."

Remove Add Old language: "to reduce illness and disability." (This implies that disability = bad/needs eradicating)

New language: "to optimize health and prevent or reduce illness for all people."

## Suggested deletions

Remove Old language: "to reduce illness and disability." (This implies that disability = bad/needs eradicating)

## Response 104

### **Reflects Strategic Plan**

I believe that the new mission statement reflects existing goals, and removes ableism from the foundation of those goals and objectives.

### Suggested additions

I have none at this time.

#### Suggested deletions

I have none at this time.

## Response 105

#### **Reflects Strategic Plan**

No response.

#### Suggested additions

No response.

### Suggested deletions

The new version is better than the older version because it does not try to prevent disabled people like me from existing but rather includes me with the rest of humanity and claims that my life is worthy of optimized health and reduced illness despite disability.

## Response 106

### **Reflects Strategic Plan**

I am writing in support of the proposed changes to the NIH MIssion Statement. It is appropriate to optimize health and prevent and reduce illness, but disability should not be equated to illness. People with Disabilities experience illness as do the Non-Disabled.

#### Suggested additions

No response.

### Suggested deletions

It is important to remove the language that equates disability with illness. This language stigmatizes and marginalizes Disabled individuals.

#### **Reflects Strategic Plan**

No response.

#### Suggested additions

"Advancing our knowledge of the nature and behavior of living systems and to apply that knowledge to optimize health and prevent or reduce illness for all people."

#### Suggested deletions

"Advancing our knowledge of the nature and behavior of living systems and to apply that knowledge to optimize health and prevent or reduce illness for all people."

Adding the word advancing really shows that we have an incredible amount of knowledge already but that we're working to add to it!

## Response 108

#### **Reflects Strategic Plan**

I think that the goals of the suggested change to NIH's mission statement 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.

#### Suggested additions

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

RATIONALE: 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.

#### Suggested deletions

No response.

## Response 109

#### **Reflects Strategic Plan**

Yes, but it feels too long. A mission statement should be short enough to be remembered by every member of the organization.

#### Suggested additions

Advancing the science of health. Searching today for a healthy tomorrow. Optimal health through discovery and knowledge.

Too wordy "nature and behavior" "optimize, prevent or reduce."

## Response 110

### **Reflects Strategic Plan**

No response.

#### Suggested additions

Something specific about addressing health disparities.

#### Suggested deletions

No response.

## Response 111

#### **Reflects Strategic Plan**

To me, illness and disability are not one in the same, and leaving out the word disability in your proposed revised mission statement could be construed as NIH does not support those with disabilities that are not caused by an illness.

#### Suggested additions

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 and disability for all people. (reason stated in the first question.)

#### Suggested deletions

None suggested.

### Response 112

#### **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.

#### Suggested additions

No response.

#### Suggested deletions

No response.

Response 113

#### **Reflects Strategic Plan**

"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." Suggested change: "To seek fundamental knowledge about the nature and behavior of living systems and to \_use\_ that knowledge to \_enable all people to attain their highest level of health\_." This phrasing was taken from the definition of Health Equity: "the state in which everyone has a fair and just opportunity to attain their highest level of health."

## Suggested deletions

It's very wordy, needs to read more smoothly, use less "and, of"

## Response 114

## **Reflects Strategic Plan**

Yes, the mission statement reflects the goals and objectives in the NIH Strategic Plan.

### Suggested additions

"To seek fundamental knowledge about the nature and behavior of living systems and to enable application of that knowledge to optimize health and prevent or reduce illness for all people." The NIH is not the only entity applying knowledge. We, in addition to our partners and the greater field of research around the world, apply the knowledge gained from NIH research and operations. "Enabling application of that knowledge" more accurately reflects NIH's role in translatability.

### Suggested deletions

None.

## Response 115

### **Reflects Strategic Plan**

As a member of the disability community, I disagree with the idea that the previous language of "reduce . . . disability" is in some way offensive to the disabled. I'd have loved if my disability could have been prevented! As this new language stands, it feels like complete erasure of disability, which I consider a step in the wrong direction.

### Suggested additions

To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to optimize health, prevent or reduce illness, and improve quality of life for people regardless of medical status or disability.

### Suggested deletions

No response.

## Response 116

### **Reflects Strategic Plan**

It does reflect on the goals better. I particularly love the prevention part. It is highly important to prevent illness. Unfortunately, in this day and age, our society seems to be

more invested in reducing illness as opposed to preventing it. Your mission statement brings a whole new light on health care. I realize they say "Do not fix it until it's broken," but if your child were to touch the stove knobs, you would most probably stop them. Similarly with preventing illness in health and well-being. I think NIH serves a noble purpose in our community and with the new mission statement, the priorities are highlighted and are more concrete.

## Suggested additions

Armenian language, please.

### Suggested deletions

n/a

## Response 117

## **Reflects Strategic Plan**

Yes.

### Suggested additions

"To expand our fundamental understanding of the behavior of living systems and to share that knowledge to optimize health, prevent or reduce illness, and improve the quality of life."

### Suggested deletions

"To expand our fundamental understanding of the behavior of living systems and to share that knowledge to optimize health, prevent or reduce illness, and improve the quality of life."

## Response 118

### **Reflects Strategic Plan**

The proposed new mission statement is good.

#### Suggested additions

No response.

#### Suggested deletions

No response.

### Response 119

#### **Reflects Strategic Plan**

I agree that the proposed change to the mission statement reflects the outlined goals and objectives.

#### Suggested additions

I do not have any other additions—I believe that this statement is clear, concise and epitomizes the goal of health equity.

N/A

## Response 120

## **Reflects Strategic Plan**

Okay, I read all 36 pages. Yes, the statement adequately reflects the goals and objectives that have been outlined. But the former statement did as well, and it did so better due to the inclusion of disability. However, the conciseness of the new statement is an improvement.

## Suggested additions

Yes, you could re-add the word "disability." Disability absolutely is and remains a state of being that SHOULD be prevented wherever possible. I am not responding as a researcher or speaking on behalf of an organization, rather, I am responding as a patient with a rare neuromuscular disability. The reason we advocate so strongly for funding research for a cure is because disability IS something to be fixed, whenever possible. There is absolutely no amount of accessibility, adaptive devices, or inclusive language that could ever have as much value as an actual cure! The implication that removing "disabilities" from the mission statement could reduce ableism is naive. The APA similarly thought that reclassifying gender dysphoria would reduce transphobia, but that never actually made life any easier for trans people. The reality of discrimination and stigma is far too complex to propose these types of solutions, which feel performative at best. Language DOES matter, but the language in the original mission statement was not problematic to begin with. Also, by nature, disability tends to be worse than most illnesses (or conditions which are generally referred to as such), because most illnesses are self-limiting and aren't disabling or debilitating. Which is all the more reason to emphasize prevention and treatment of disabilities, not to shy away from using the word at all. If anything, I fear this change will make it harder to advocate for cures. I mean, why should we, if disability doesn't really "need to be fixed"?

### Suggested deletions

No, but I think even the substitution of the word "disease" for "illness" in the new statement would be preferable, if disability absolutely MUST be removed. "Illness" is too often associated with acquired conditions or an infectious etiology. "Disease" is colloquially broader and still encompasses conditions that commonly cause disability. For example, most people might not consider obesity or addiction an illness, but they might still consider both a disease. Or, despite possible redundancy, the new statement could include BOTH "disease" and "illness."

## Response 121

## **Reflects Strategic Plan**

I support the use of the new mission statement.

### Suggested additions

No response.

## Response 122

#### **Reflects Strategic Plan**

I very much like the motivation to tweak the mission statement to be more inclusive. Well done! I like the change to include "for all people." I like the change to an active verb "to apply."

#### Suggested additions

No response.

### Suggested deletions

I like the edits, but think we could streamline more. I think the "...and prevent or reduce illness..." phrase is a bit awkward. Perhaps streamline even more?

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

## Response 123

#### **Reflects Strategic Plan**

The new mission statement is good. But the prior one was just as acceptable. What led to this change is itself problematic. It is a problem that disability is interpreted as an intrinsically negative feature or flaw. Perception and interpretation of something as flawed is subjective. Whether or not someone or something is or is not physically able to do a particular task is an objective fact. We should not avoid dealing with objective facts to enable a potential subjective misperception. The fact that this has resulted in large-scale opinion-seeking means that an enormous amount of time and effort have been taken to create a problem that didn't exist and then work to fix it. We should spend time and effort more wisely.

#### Suggested additions

No response.

### Suggested deletions

No response.

### Response 124

### **Reflects Strategic Plan**

A major issue that is not addressed here is the access to breakthrough treatments TO ALL PEOPLE that results from the the fundamental knowledge. As the largest health research institute in the world, NIH has a moral responsibility to have a say in this issue for the tax payers. This falls into the concept of strict ethical stewardship of the resources spent on behalf of the public. It is currently not addressed at the highest levels at NIH, blaming the statutory limits imposed by the congress, and heavily lobbied by the Pharma industry. NIH

should be transparent in the public and at the congressional level to address this issue. Even as a veteran of the pharmaceutical industry (now retired) it is an ethical issue NIH should take the lead. Passing the buck down the road does not serve the public.

### Suggested additions

Suggested edits to new mission statement:

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

Quality of life is very important to "optimize health rand prevent or reduce illness." In many cases (cancer and Alzheimers for example), optimizing health is closely related to quality life post treatment. Secondly, prevention and cure is important as in the NIH Strategic Plan.

## Suggested deletions

None. The new mission with the addition of "cure" and "quality of life" is quite appropriate. The word disability has been removed which is fine, but the addition of "quality of life" in the context of optimized health outcomes is quite important.

# Response 125

### **Reflects Strategic Plan**

Yes, I think that the new mission statement does reflect the goals.

#### Suggested additions

I like the additions of optimize, prevent, and all people.

#### Suggested deletions

No response.

## Response 126

#### **Reflects Strategic Plan**

Not to the fullest.

#### Suggested additions

"To deeply comprehend the workings of life and use this knowledge to improve the wellbeing of the global population, focusing on extending lifespans, reducing illness, and promoting mental health using minimally invasive methods."

#### Suggested deletions

No response.

### Response 127

### **Reflects Strategic Plan**

I support the proposed change of wording, especially including "optimize health" for all people. That names it clearly.

No response.

### Suggested deletions

No response.

## Response 128

### **Reflects Strategic Plan**

No response.

### Suggested additions

I wonder about adding in language around wellbeing or quality of life (e.g., "to apply that knowledge to optimize health AND WELLBEING and prevent or reduce illness for all people")—many disabilities are lifelong and the goal is to optimize quality of life/add supports and services rather than any kind of prevention/reduction of symptoms or illness.

#### Suggested deletions

No response.

## Response 129

### **Reflects Strategic Plan**

I support the adoption of a less ableist mission statement. I believe the proposed mission statement is a significant improvement.

### Suggested additions

Specific language around "engagement" "participation" "well-being" or "inclusion" should be considered. Health is nice but is not in and of itself a goal. The real goal is to be healthy in order to engage/participate in society and live a meaningful and fulfilling life.

### Suggested deletions

The language "to optimize health" would benefit from additional reflection. It is unclear if things like Deafness, Autism, or other disability cultures are things that may be "optimized" out.

## Response 130

### **Reflects Strategic Plan**

The addition of prevention to the mission statement aligns with a main sub-objective in the NIH strategic plan. The emphasis on research for all people is critical for a federally funded organization.

### Suggested additions

No response.

## Response 131

### **Reflects Strategic Plan**

I see the argument for removing the word "disability," but the "prevent or reduce illness" part of the new statement doesn't cover research into preventing or recovering from firearms injuries, traumatic brain injury, or other non-disease events. Maybe this kind of research is covered by "optimize health."

### Suggested additions

The revised language "to apply" is a good change because it resolves the earlier ambiguity about whether the existing mission statement parses as "To seek (a) fundamental knowledge ... and (b) the application of that knowledge..." or "To seek fundamental knowledge about (a) the nature and behavior of living systems and (b) the application of that knowledge ..."

Is there a reason the language uses "to optimize health" rather than "to improve health"? "Optimize" suggests there is some known optimal state of health.

#### Suggested deletions

No response.

### Response 132

### **Reflects Strategic Plan**

It appears to be aligned with the goals and objectives of the Plan, with the suggested addition and removal of specific language to further enhance its clarity and focus.

#### Suggested additions

Consider including an emphasis on interdisciplinary collaboration and innovation, as those are key components of the strategic plan. For example, you can add verbiage such as "through interdisciplinary collaboration and innovative approaches."

#### Suggested deletions

The phrase "for all people" in the proposed statement can be removed as it appears to be redundant.

### Response 133

#### **Reflects Strategic Plan**

No response.

#### Suggested additions

The proposed mission statement omits the concepts of increasing longevity and reducing disability. I would like to see those two concepts returned to the mission statement.

No response.

## Response 134

## **Reflects Strategic Plan**

I feel it does accurately reflect the goals and objectives outlined in the Strategic Plan. I appreciate the removal of the phrase "to reduce disability"—I am a NIH employee with a disability, and I feel that I add to the agency! I don't want to be "reduced," I just want to be accepted and accommodated (something that I overall feel that NIH does quite well!).

## Suggested additions

None

## Suggested deletions

What about simply rephrasing to "To seek fundamental knowledge about the nature and behavior of living systems and to improve health for all people"? No doubt you've had countless workgroups and brainstorming meetings, but the proposed mission statement feels a little clunky (and would probably feel especially clunky to a lay person). It also probably won't roll off the tongue well when the higher-ups have to include it in any of their speeches.

## Response 135

### **Reflects Strategic Plan**

Yes, the proposed revised mission statement aligns with the strategic plan.

### Suggested additions

No additional suggestions.

### Suggested deletions

"To seek fundamental knowledge about the nature and behavior of living systems and apply that knowledge to optimize health and prevent or reduce illness for all people." My suggestion removes the "to" before "apply" and makes for a cleaner read. This does not detract from the meaning or intention of the statement.

## Response 136

## **Reflects Strategic Plan**

I find the new mission statement represents a step backwards for the agency. Subordinating the obvious and important mission of \*actually doing good\* to the meaningless semantic treadmill that is nowadays popular dilutes the clear and important message that it is fixing disabilities, not the feelings of those who are disabled, that currently is and should remain the goal of science.

### Suggested additions

Removing "lengthening life" from the mission statement in favor of "optimizing health" is a mistake, just as is removing the explicit goal of reducing disability. Disability, as I'm sure we

can agree, is a bad thing. Disabled people are obviously not morally inferior as people! But it is worse to be blind than sighted, have deadness than the gift of hearing, etc.

This updated mission statement shows a change from the explicit and concrete: lengthening life and reducing disability, to the nebulous and abstract: "optimizing health." While you could certainly argue the latter encompasses the former, it is the ability to argue that is gained by increasing the abstraction of the mission statement—not something of value.

### Suggested deletions

The mission statement should not be updated. I urge the NIH to retain the original mission statement and discard the proposed update.

## Response 137

### **Reflects Strategic Plan**

I believe so.

#### Suggested additions

None needed.

#### Suggested deletions

My only hesitation is on "prevent or reduce illness for all people." I get that this is a mission statement, and, therefore, can be somewhat aspirational, but I don't know if preventing illness is realistic. What I think can be realistic is preventing the \*burdens\* that come with illness. I also think that "preventing or reducing illness" verges into ableist language.

## Response 138

### **Reflects Strategic Plan**

No response.

### Suggested additions

Reduce the impact of disability or some iteration of this. Taking out disability erases people with disabilities. Isn't the goal to adapt society on such a way that people with disabilities live full lives and particular fully in society with fewer barriers?

### Suggested deletions

No response.

### Response 139

### **Reflects Strategic Plan**

NIH mission...suggest adding "prevent" and reduce illness and disability.

Goals: second bullet—to develop, maintain and renew research capacity, both human and associated resources, to ensure the Nation's capacity to prevent disease and to promote population health.

Goals: third bullet—to expand the knowledge base in the health and related sciences in order to enhance the Nation's physical, mental and social well-being...

In realizing these goals, the NIH provides leadership...by conducting and supporting biomedical, behavioral and social sciences research:

first bullet—in the causes, diagnosis, prevention, treatment and rehabilitation of human diseases;

fourth bullet—in the biological, behavioral and social understanding of mental, addictive and physical disorders;

fifth bullet—in directing programs...of information in health, including the development and support of health libraries and the training of librarians and other health information specialists.

## Suggested additions

Suggested changes listed above reflect the addition of all health disciplines beyond the medical category and encompass the social determinants of health and illness. The changes additionally include the science underlying prevention and health promotion to ensure the complete spectrum from basic to implementation science is included in the NIH mission.

### Suggested deletions

No response.

## Response 140

### **Reflects Strategic Plan**

Pitting the idea of inclusivity against the need to help people with health related problems that lead to disability seems unwise. One can be inclusive of people and yet help reduce their burden, whether that burden is physical or mental. All chronic illnesses, in some ways, represent a decrease in function and therefore a form of disability. If the mission statement states that its goal is to reduce illness, does that constitute a prejudice against ill people?

If an individual does not wish to reduce their disability, that is their choice and it needs to be respected. But one cannot, in the process, deprive people who struggle with disabilities from the hope that research will help them overcome their struggles or lessen their burden.

#### Suggested additions

Proposed:

To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to optimize health, prevent or treat illness, and reduce the burden of disability.

Why: By saying the "burden of disability" allows any given person to determine whether or not they consider a disability burdensome, and also how the onus can be reduced even if the disability itself cannot be reversed. For example, the burden of losing speech can be reduced via new strategies for communication.

#### Suggested deletions

## **Reflects Strategic Plan**

Yes. Eloquent. I prefer the revised statement.

#### Suggested additions

No response.

#### Suggested deletions

No response.

## Response 142

#### **Reflects Strategic Plan**

The choice to use "optimize health" is an excellent one. This is a much better way to phrase what the NIH and all heathcare providers are trying to do. This matches the strategic plan.

#### Suggested additions

NA

#### Suggested deletions

NA

## Response 143

### **Reflects Strategic Plan**

I understand that "reduce disability" could be seen as stigmatizing to those who have a disability. But disability is a social construct, so reducing disability doesn't mean getting rid of people who are disabled. It means making the world a less disabling place for people who have limitations in various ICF domains. "Reduce illness" takes us right back to the medical model, and the notion that the only way to be able bodied is to have all of ones' diseases cured. What about "reduce illness and disablement," to emphasize that it's the process we want to change?

#### Suggested additions

What about "reduce illness and disablement," to emphasize that it's the process we want to chang.

#### Suggested deletions

No response.

### Response 144

### **Reflects Strategic Plan**

I think it is a mistake to remove disability from the statement, because as it is proposed, it implies a more curative approach, which is not sufficient. Ok to just reduce illness, but what happens after?? I don't think the proposed mission statement adequately addresses the after...

... address limitations due to impairments and improve quality of life for all people.

This addition would capture the importance of rehabilitation and participation.

### Suggested deletions

I propose to modify the latter part of the proposed mission from "to optimize health and prevent or reduce illness for all people"

TO "to optimize health, prevent or reduce illness, address limitations due to impairments and improve quality of life for all people."

OR "to optimize health, prevent or reduce illness, and improve quality of life for all people."

## Response 145

## **Reflects Strategic Plan**

Mostly. "Optimize health and reduce illness" is better than "enhance health, lengthen life, and reduce illness." However, the removal of "reduce...disability" will harm NIH's ability to "turn discovery into health" by taking focus away from the psychosocial & environmental components of health.

## Suggested additions

Add "and disability" after "illness." These two terms are not synonymous, and American health is best improved by a holistic picture that includes the interaction between the body and environment (i.e., disability), not just the body in isolation.

### Suggested deletions

No response.

## Response 146

### **Reflects Strategic Plan**

I support the change in the mission and am glad to see the addition of "for all people."

### Suggested additions

None.

### Suggested deletions

None.

## Response 147

### **Reflects Strategic Plan**

First, let me state, I am an individual with a disability, and people that want to ignore that, even those with disabilities, really disturbs me. My disability is fully integrated into my identity, and I see NOTHING wrong with trying to minimize disability or maximize my abilities!!!!!! The working group obviously did not represent all view points. EVERYONE has disabilities and we are all diagnosable. We should ALL be afforded the opportunity to

maximize our health, wanting to 'not' talk about it is patronization at its best. It ranks up there, with—you are so inspiring—why because I have the audacity to continue breathing. I am perfectly aware of my abilities and disabilities. I should be afford that grace by everyone. This is just like the people who turn their head when I walk down the street or look me in the eye after starring and get embarrassed. Disability status will NEVER become part of the spectrum of diversity until we treat it as such, as part of all of us. And, we will never get the funding we deserve to maximize life and health for individuals with disabilities until we recognize their are things to maximize!!! That means recognizing the fact that maximizing abilities and minimizing disabilities are sometimes, not always, but sometimes two halves of the same coin.

### Suggested additions

### At a minimum.

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

### Suggested deletions

No response.

## Response 148

### **Reflects Strategic Plan**

I like the switch to "to apply," as it makes more sense grammatically and logically than the previous version.

### Suggested additions

I strongly oppose eliminating the goal of reducing disability. I study Parkinson's disease. A lot of important progress in that field has NOT contributed to "preventing or reducing illness" but has instead contributed to "reducing disability"—that is, increasing people's ABILITY to lead full, active lives, whether via medication, exercise, or other approaches.

#### Suggested deletions

I like enhance (in the current mission statement) better than optimize (in the proposed statement). "Optimize" suggests striving toward a narrow ideal state. "Enhance" is more open-ended.

## Response 149

### **Reflects Strategic Plan**

No response.

### Suggested additions

I think you should add to the start of the mission statement these words: Without political motivation and the silencing of certain ideological or scientific viewpoints, we seek.

It is clear that scientific debate has been corrupted by political viewpoints. Cramming certain ideologies down people's throats while silencing others. There is lack of objective thinking at this time, and it saddens me.

### Suggested deletions

It's not very plain language. Maybe try again so that the America public can understand it. Think of the literacy level in this country.

## Response 150

## **Reflects Strategic Plan**

I understand that many in the disability community feel their disability is part of who they are, and that the language "reduce disability" is problematic for that reason. But the purpose of reducing disability it so improve functioning, and I believe both the old and new mission statement miss the opportunity to highlight the role of NIH in identifying ways to improve function.

### Suggested additions

## Add: "optimize function"

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

### Suggested deletions

No response.

## Response 151

### **Reflects Strategic Plan**

No response.

### Suggested additions

Keep the "lengthen life" line from the old mission statement. Not only does that directly reflect some of the purposes for existing NIH divisions (i.e., NIA), but furthermore the lengthening of life is different yet equally valid to optimization of health and reduction/prevention of illness. Neither of those inherently lead to longer lives for all, and yet we want to help people live longer lives than they already do. This is particularly prescient given the US doesn't lead the world in life expectancy, and so a US-based research institution—even with international reach and funding—should emphasize the lengthening of life, and allowing people to not only live an optimally healthy life, but a long one.

### Suggested deletions

"People" at the end is unnecessary. This is not only for concision's sake, but also because NIH research has a non-zero effect on animal wellbeing, something that—while not directly part of NIH's primary targets—is still something of value that NIH research contributes to.

### **Reflects Strategic Plan**

The proposed mission statement nicely captures Objective 1 of the NIH-Wide Strategic Plan: "Advancing Biomedical and Behavioral Sciences." However, it does not capture Objectives 2 and 3, which deal with supporting research capacity and integrity. Also, it's odd that "while NIH's primary mission is the conduct of research," (per the Strategic Plan and per common understanding of NIH staff, leaders, and stakeholders), the word "research" does not appear in either the current or proposed mission statement.

### Suggested additions

There's a lot to like about the proposed mission statement, in addition to dropping "disability." First off, thank you for removing "lengthening life." A longer life surely is not much benefit without improving health and probably should be discouraged at some point, since death is a natural and necessary part of living systems. Is it possible to go even further and say that NIH supports research to improve "quality of life" as opposed to just quantity? I also love the change from "application" to "apply." Hooray for active voice!

There are a few word changes that I think make the statement more complicated and less readable than it should be. I don't like "optimize" over "enhance." (Shorter words are always better, all things being equal.) Nor do I think the statement needs to include "preventing" illness, because to my mind, "reducing illness for all people" would encompass prevention and treatment. Whoever added "prevent" seems to think that "reduce" means "treat," which it doesn't. Given these small quibbles and the larger issue of better aligning the statement with the actual NIH mission (research) and strategic plan, I would revise it to something like this: "To support fundamental research into the nature and behavior of living systems, to apply this research to enhance health and quality of life for all people, and to sustain research capacity and integrity for the health of future generations."

### Suggested deletions

Please see my previous comments and proposed revisions to the statement. Thank you for your work to revise it and for soliciting input!

# Response 153

### **Reflects Strategic Plan**

I think it does.

### Suggested additions

None

### Suggested deletions

None—I like the omission of disability in this version and the active voice.

#### **Reflects Strategic Plan**

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 and disability for all people.

#### Suggested additions

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 and disability for all people.

I like the inclusion of disability in the mission statement. There is scientific evidence that this can also be accomplished.

#### Suggested deletions

None.

## Response 155

#### **Reflects Strategic Plan**

While the new mission statement achieves the objective regarding disability, it does not define what is meant by health. I suggest adding the qualifier of "whole person health" to suggest that the focus is broader than biological health and considers all facets of health and wellbeing. I'd also suggest that we aim to better manage illness in the case of chronic diseases with no current cure.

#### Suggested additions

To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to optimize whole person health and prevent or reduce illness while optimizing quality of life for all people.

#### Suggested deletions

No response.

### Response 156

#### **Reflects Strategic Plan**

Yes; healthcare should not be an entitlement only for those with money. It should be an integral right for all regardless of socioeconomic standing, race, religion, creed, or country of Origen, and or religion. This should be governed for humanity as a whole.

#### Suggested additions

This should be governed for humanity as a whole.

#### Suggested deletions

### **Reflects Strategic Plan**

No response.

#### Suggested additions

I would love to see the statement include the word "cure." "....to optimize health and prevent, reduce or someday cure illness for all people." Is it too hopeful to use a word like cure? I believe in science and am hopeful and expectant that the medical community will cure cancer and other maladies in the future. I have faith that all the wonderful people that choose careers in medicine will continue to improve life for all people. We have come so far in the last 100 years. I think people forget or don't know how it used to be before modern medicine. Positivity goes a long way.

#### Suggested deletions

No response.

## Response 158

#### **Reflects Strategic Plan**

I like the new proposed statement. It proved a clearer indication of what the knowledge will be used for and for whom. This country does not have systems that are geared for the common good of the health of the people. We have gone further and further into profits over people. I would like to see public health initiatives reason for organic healthy food and how it supports our microbiome and each body system. People now believe that it wouldn't be sold to you if it wasn't safe. We used to have 80% of the population involved in farming and ranching. People knew where their food came from and the need for healthy soil. Now 1% of the population is involved, and it is big agribusiness that does not care about the quality of the food. I want our government to be concerned about the quality of the food given to its citizens; Big Ag is no different than the big military complex that President Eisenhower warned of. Profits over people must stop before our greed has lead to our extinction. As a nurse of 41 years, I have watched healthcare change continually for the worse and the health of our people and our planet diminish. Please make a real change.

#### Suggested additions

No response.

#### Suggested deletions

No response.

### Response 159

### **Reflects Strategic Plan**

Like the proposed mission statement as distributed. It is more inclusive and specifically lists all people as its target. Thank you!

#### Suggested additions

No response.

## Response 160

### **Reflects Strategic Plan**

The fact the mission statement wording needs to be changed or taking too much attention from applying your mission statement to study wording of your statement says to me words are more important than action. Applying your goals in actuality would enhance so many lives of people suffering everyday while your terminology changed nothing for them. Where are your priorities? Words or deeds? Apply your mission and get rid of deadwood that have time to study and propose nothing that helps and hire more people whose goal is to find ways to apply your mission statement. Your budget needs to be increased on the side of deeds and your expenditure on administration decreased.

#### Suggested additions

No response.

#### Suggested deletions

No response.

## Response 161

### **Reflects Strategic Plan**

No, it does not at all.

No change is required at all.

### Suggested additions

You have to acknowledge that illness if not successfully treated can result in death, permanent limitation in function or restoration to normal pre disease state functioning.

The language must acknowledge that disease can result in permanent limitations in functioning. In not acknowledging disabilities that result from illnesses you are, in fact, eliminating that sub group of individuals.

### Suggested deletions

Stating that you're only going to be addressing illnesses in all individuals.

## Response 162

### **Reflects Strategic Plan**

Illness by definition does not include groups with limitation and function.

The new mission statement, in fact, ignores that sub group of individuals who have limitations in function, that a result of illness. The definition of illness does not include disabilities or limitations and function.

No change is required perhaps using the definition of disability.

### Suggested deletions

Need to include patients with disabilities.

## Response 163

### **Reflects Strategic Plan**

No response.

### Suggested additions

No response.

### Suggested deletions

The phrase "optimize health and prevent or reduce illness for all people" is tautological, ill defined, and open to speculative interpretation. The specific concern is with regards to the word "optimized." If optimized health is health devoid of illness, the phrase "...prevent or reduce illness for all people" is sufficient to convey the point. Yet "optimize health" could also encompass not only the reduction of suffering and the burdens of illness and disease but also attempts to "improve" the health of otherwise healthy individuals. "Optimized" health, if health is considered holistically, is not currently nor necessarily possible to define in such a manner that is not inherently subjective. One person's health could entail a long life. Another's could be the pursuit of personal fulfilment or happiness. Similarly, optimal is not possible for all persons. While the "optimal" solution for a person addicted to opioids may be that they never desire to use illicit substances again, this end point may not be feasible. What's more, its pursuit may come at the cost of other treatments with less "optimal" endpoints that could otherwise enhance a person's quality of life. The use of "optimize" in the mission statement is unnecessary, opens the door to selective interpretation of the correct path for agency funding, and could lead to exclusion or omission of critical areas of research based on the personal beliefs of the funding source. This word should be removed.

# Response 164

### **Reflects Strategic Plan**

Yes.

### Suggested additions

No response.

### Suggested deletions

"optimize health and prevent or reduce illness" is kind of an awkward phrase because it has 2 different conjunctions right next to each other. Perhaps there is another way to phrase this that flows better.

## **Reflects Strategic Plan**

NIH's mission is to turn discovery into health. The new mission statement is too vague. The most important discovery in the last 20 years is that plant-based nutrition can prevent and reverse some of the most common causes of premature death and disability—the highly refined and animal-based food we eat. A recent article in the *International Journal of Disease Reversal and Prevention* illustrates why it is important to be specific. The researchers in the article found that only 11% of cardiologists consume the healthy diet they prescribe to their patients. Cardiologists know that a whole food plant-based diet is best for their patients, but most of them have not turned this discovery into health for themselves. You can't turn discovery into health. It's following the healthy lifestyle that does the job. GET SPECIFIC if you want healthy outcomes. By not being specific, providers of disease causing foods such as cured meats will have a field day touting how their cancer causing products are healthy.

### Suggested additions

"To seek fundamental knowledge about the nature and behavior of human beings and to apply that knowledge, especially our current knowledge about whole food plant-based nutrition, to optimize health and prevent, reverse, or reduce illness for all people."

The specific language added above is "human beings" in place of "living systems," and "especially our current knowledge about whole food plant-based nutrition," and "reverse." Preventing and reducing illness is important. But your mission should also be to REVERSE heart disease, diabetes, hypertension, and other diseases that the meat-based diets in the USA cause.

Human beings have nutritional and other requirements for health vastly different from most other living systems. You want your mission statement to make sense to people who read at the 8th grade level, maybe lower. Most college educated people already know that plantbased nutrition is the best for their health, they just need a doctor who will encourage them make the change. But most other people need to know specifics, not abstractions. The current proposed mission statement may appeal to academics and nerds. You want it to appeal to everyone, yes, especially the people at the NIH.

### Suggested deletions

"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."

As noted in my previous statements, "living systems" should be removed and replaced by "human beings." Yes, many people at the NIH may be doing research on rats, chimps, etc., but their goal should be to apply their findings to human beings.

## Response 166

### **Reflects Strategic Plan**

Agree.

No response.

## Suggested deletions

No response.

## Response 167

## **Reflects Strategic Plan**

The mission statement appears to be narrower in scope than what is presented in the NIHwide strategic plan. While I appreciate the desire to make the mission statement more broad, in doing so it suggests a lack of interest in uncommon conditions. Would a grant proposal to investigate a rare genetic disorder be rated poorly on significance as its findings wouldn't benefit the health of "all" people? Likewise, on its own, removal of language related to reduction of disability is benign, but the rationale is concerning. While disability has become a component of identity, and the choice of whether to remediate a disability is an individual one, it can still be a goal of the NIH to reduce disability or, at least, support development of the means to do so. As above, would a grant proposal with a primary goal of developing a disability-reducing device or treatment receive a low priority score on the grounds of being ableist? As written, the revised mission statement does not reflect NIH goals, and, if the rationale for removing language regarding disability persists, will need to be revised again should illness status become an identity, in which case a goal of reducing illness would also be ableist.

### Suggested additions

No additional language is required.

### Suggested deletions

"and prevent or reduce illness for all people" could be removed. A mission statement of "To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to optimize health" would encapsulate NIH goals and objectives without implying a narrowed interest in population-wide outcomes. In addition, "optimize health" is a broad enough concept to contain a diverse set of research goals.

# Response 168

### **Reflects Strategic Plan**

Yes, it meets the goals and objectives simply by adding "all people" and removing "disability."

### Suggested additions

Replace "people" with "peoples." I suggest this because "people" in this context sounds like as a species as opposed to "all living things". By replacing with "peoples" it both unites us as a species (yes!) and allows for us to be unique in our identities. I would refer to this concept as approaching it as a "holon," or an entity in an of itself while remaining defined by relation to the whole. Singular and plural: peoples.

Could be simplified without losing meaning. Except, why use the word "fundamental" when the work is so specific in so many instances? Why differentiate between fundamental and specialized?

"To seek and apply knowledge of the nature and behavior of living systems to optimize health and prevent and reduce illness for all [peoples]."

## Response 169

### **Reflects Strategic Plan**

Yes, does reflect goals and objectives, and the revised statement is more succinct and equally clear as the current statement.

### Suggested additions

No response.

### Suggested deletions

No response.

## Response 170

#### **Reflects Strategic Plan**

It does not as it continues to fund research on animals of all types in the USA & foreign countries.

### Suggested additions

To seek fundamental knowledge about the nature & behavior of humans & animals of all kinds without animal research of any kind to gain knowledge etc., etc.

#### Suggested deletions

Remove the word systems that allow the abuse of animal experiments for research that can be done using MORE modern methods.

## Response 171

### **Reflects Strategic Plan**

Include Marathi and Hindi Languages, since both are official languages in India and are spoken by large number of people, some of them may not know English. These people depend heavily on Alternative Medicine.

#### Suggested additions

No response.

#### Suggested deletions

#### **Reflects Strategic Plan**

No response.

#### Suggested additions

My suggestion applies to the section of the mission statement: to apply that knowledge to optimize health, prevent or reduce illness, thus lengthening life for everyone.

#### Suggested deletions

No response.

## Response 173

### **Reflects Strategic Plan**

No response.

#### Suggested additions

All areas of society should be addressed by national newsbreaks to citizens about new advances in health and healing. You test and test, and we the public have no clue what you have discovered.

#### Suggested deletions

Send information to grassroots organizations for dissemination to actual citizens.

### Response 174

#### **Reflects Strategic Plan**

Yes, but work to reflect not just translation of basic science but also application of clinical science. See suggestion below.

#### Suggested additions

Add "and practical" after the word "fundamental" to reflect interest in both basic and applied discovery that can lead to impact both short and long term.

#### Suggested deletions

No response.

## Response 175

#### **Reflects Strategic Plan**

The proposed new mission statement appears to be more inclusive by stating "all people." Of greatest interest and support from me, the new language specifically states to "prevent" illness. The prevention piece has historically been taken for granted, but given how funding decisions have been made at the panel review level of NIH awards, the prevention impact of proposed research endeavors was sometimes lost upon reviewers. The prior language focusing mainly on the enhancement of health led to greater focus on downstream consequences of income, diet, behavior, environmental exposures, etc. I am greatly enthused by seeing the word "prevent" in the new mission. Its long overdue. NIH is not a National Institutes of Medicine; it is nice to see the focus include the prevention aspect of 'health.'

My profession is academic and my research pertains to the health of human illness among Appalachian populations in Eastern Kentucky. "Prevention" is a term of tremendous relevance; however, the majority of the focus at NIH related to this population has been focused on also needed "treatment" of existing illness, to some degree with a heavy omission regarding "prevention." I know of many who are enthusiastic to see NIH welcome the term "PREVENT."

## Suggested additions

NIH has the potential to more clearly illustrate how the work of NIH broadly impacts society. The NSF, for example, has review criteria related to research that has broad impacts for the American people at-large. NSF also acknowledges the value of promoting our national defense. Currently, our national security is actively being compromised by the health of our U.S. population. Therefore, the NIH may learn from some aspects of the NSF mission on better articulating the importance of NIH-funded research for the benefit of society at-large, and not just individuals. The current approach by NIH still has a very heavy 'patient' or person focus. While the new proposed mission statement does improve inclusivity (for all people), the societal benefits of NIH research are worthy of consideration.

A proposed suggestion is as follows:

"To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to broadly impact society and individuals by optimizing health and preventing or reducing illness among all people."

It is vital that American persons can see how NIH broadly impacts all Americans. NIH needs to be prepared to combat the individualistic nature of American society, and somehow, the valuable work done by NIH has to be seen in a way that the work benefits our nation and not just certain populations. The use of the language of supporting "all persons" in the NIH mission is a major step forward. However, work that benefits populations or society is also important for 'broadly' impacting everyone.

## Suggested deletions

No change recommended for language to be removed from the new draft language.

# Response 176

## **Reflects Strategic Plan**

The statement most certainly does not reflect the goals and objectives of NIH. While removing the language about disability to avoid perceptions of stigma against disabled people is a good and noble change, removal of "lengthen life" is misguided, not reflective of the subgroup's recommendations. Moreover, this omission does not add value to the mission statement but rather directly eliminates an important goal and direct mission of many of the individual institutes, notably NIA.

Removal of disability is a good decision. However, "lengthen life" should not be removed. I suggest: "To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to optimize health, lengthen life, and prevent or reduce illness for all people." It is not enough that optimized health and reduced illness imply longer life; long life must be an explicitly stated goal of NIH to reflect the reality of the what we as scientists work for.

### Suggested deletions

None.

## Response 177

## **Reflects Strategic Plan**

No response.

### Suggested additions

To COMPILE fundamental knowledge about the nature and behavior of living systems, PROMOTE that knowledge to optimize health and reduce illness for all.

### Suggested deletions

No response.

## Response 178

### **Reflects Strategic Plan**

Suggested mission statement: "To pursue a comprehensive understanding of the intricacies of living systems and utilize this knowledge to enhance health, while striving for the well-being of all individuals."

### Suggested additions

Suggested mission statement: "To pursue a comprehensive understanding of the intricacies of living systems and utilize this knowledge to enhance health, while striving for the well-being of all individuals."

### Suggested deletions

Hard to achieve "optimized health."

Remove "illness."

## Response 179

### **Reflects Strategic Plan**

This is one part of a long overdue plan to optimize national health and welfare. Also, disability really should be considered the sixth social determinants of health, which the NIMHD has yet to do and needs to!

I am not sure where specifically we could include this, but I think a good idea would be to include some discussion of the social model of disability in the effort to optimize health and wellness for all people. Adopting the social model, design thinking, and universal design for learning and education, as opposed to the medical or moral models or operating on a "special education" model which reeks of ableism, is critical to ensure that people with disabilities encounter fewer health disparities in their quest to live their best lives.

### Suggested deletions

No response.

## Response 180

## **Reflects Strategic Plan**

The new mission statement matches the goals and objectives outlined in the NIH Wide Strategic Plan.

## Suggested additions

I am concerned about the removal of "lengthen life." While I believe this was done to focus on optimizing health, the lack of recognition of the need to extend the lifespan and healthspan, particularly when the average US life expectancy is dropping, seems to be a mistake. One that should be included—along with healthspan—in the language of the NIH Mission.

I am also concerned the removal of the term "disability" will result in it being an area the NIH does not focus on or fund. While we do not want to portray all disabilities as the same, the reality is that there is a need to address and prevent some disabilities from occurring.

I would strongly suggest extend life expectancy or some other term be used.

### Suggested deletions

I believe the "or" should be replaced with an "and"—prevent and reduce illness.

It is not an either/or, we can do both.

## Response 181

### **Reflects Strategic Plan**

I believe the proposed new mission statement reflects the goals and objectives in the NIHwide strategic plan and am supportive of the change.

### Suggested additions

No response.

### Suggested deletions

### **Reflects Strategic Plan**

Yes, the new one does.

### Suggested additions

The proposed revision removes problems with the current statement. The new one is better.

#### Suggested deletions

No response.

### Response 183

#### **Reflects Strategic Plan**

No. Removal of the word "disability" is a dangerous initial step to actually EXCLUDE disability from the mission of NIH—not an action toward inclusion. Extending the same rationale to remove disability from the mission statement, one can argue that many socially sensitive matters such as mental "illness" or hereditary disorders should be removed from the NIH mission because identifying such conditions as being "flawed and need to be 'fixed."

#### Suggested additions

I recommend to keep the current mission statement without removing the word "disability."

#### Suggested deletions

None.

## Response 184

#### **Reflects Strategic Plan**

I support the revised mission statement. Yes; however, it could be improved if it also stated a goal to "improve quality of life" after optimizing health in the revised mission statement.

#### Suggested additions

Yes, add to "improve quality of life."

#### Suggested deletions

As someone living with brain injury and moderate to severe asthma, which are two distinct disabilities, your new definition doesn't go far enough. Yes, we want to be healthy and prevent illness, but many times a brain injury is not from an illness; it is from an accident. We want improved quality of life outcomes since we have to live with lifelong brain damage from an accident that caused our disability, because we can't be returned to our former levels of brain health. With regard to asthma, your definition makes sense.

### Response 185

#### **Reflects Strategic Plan**

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

There is a direct correlation between safety and health. Safety skills and behaviors are intertwined with health.

### Suggested deletions

No response.

## Response 186

### **Reflects Strategic Plan**

I am the parent of a 23-year-old with Down syndrome and I support the proposed new mission statement.

### Suggested additions

No response.

#### Suggested deletions

No response.

## Response 187

### **Reflects Strategic Plan**

Yes; I understand the intent of "reducing disability," but I also see where some community groups would take issue with that statement.

### Suggested additions

Revision to the 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 \*preventable\* illness" or revision to the proposed 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 \*and the unborn\*"

### Suggested deletions

n/a

### Response 188

### **Reflects Strategic Plan**

I support the new mission statement as presented.

### Suggested additions

No response.

## Response 189

## **Reflects Strategic Plan**

Insufficient knowledge to comment.

## Suggested additions

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

As a consumer/citizen and former student, one of the most important things about NIH is the free access to research and to the knowledge derived from that research.

### Suggested deletions

"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."

The word "apply" seems overly broad and so a bit scary. Too open to interpretation by administrations who might make decisions about application of knowledge (e.g., to determine that young women shouldn't have access to contraception for some reason, or that condoms should require a prescription). I think the research itself and dissemination of knowledge should be the primary focus.

# Response 190

### **Reflects Strategic Plan**

Honestly, I think it is ridiculous to make this change. I'm shaking my head in disbelief. If something can be done to make someone more "able," why wouldn't you do it? It doesn't mean that you don't value the person. I just don't get it. I am a parent of two autistic young adults or young adults with autism depending on your language preference. Much more study and research needs to be done on this group of individuals to help them to live their best life.

### Suggested additions

Leave it the way it is. You could add additional language to appease whomever doesn't want their disability reduced. I'm not trying to be facetious in saying this. Maybe appease is the wrong word. I respect that many people might embrace a condition that others consider a disability and that is, of course, their right.

### Suggested deletions

Don't change it.

## Response 191

## **Reflects Strategic Plan**

Yes

The suggested change is very good. Don't change it.

### Suggested deletions

No response.

## Response 192

## **Reflects Strategic Plan**

Thank you for proposing language stigmatizing disability. I appreciate the focus on optimizing health and the work of preventing or reducing illness for all people.

### Suggested additions

No response.

## Suggested deletions

No response.

## Response 193

## **Reflects Strategic Plan**

Didn't read the plan but I think the new proposed mission statement is better.

## Suggested additions

N/a

### Suggested deletions

N/a

## Response 194

### **Reflects Strategic Plan**

The proposed language seems to reflect the NIH-Wide Strategic Plan for Fiscal Years 2021–2025.

### Suggested additions

As a person with a disability who is also old, I am both personally worried and in disagreement with state and federal programs that inadequately adhere to the requirement of being able to live in the community in the least restrictive environment in accordance with the American with Disabilities Act and any other applicable state and federal civil rights and disability protection laws, due to the failure of elected officials and agencies to provide the financial support that a lower-income disabled person may require to survive on one's own, to be able to maintain housing, to afford medical care not completely covered by insurance co-payments and deductibles, and to be able to afford transportation costs such as car repairs, auto insurance, and yearly state licensing fees. That language is lacking right now and thus is unclear that many disabled people are not eligible for so-called wrap-around services, and yet, do not have enough income and lifelong assets to be able to

adequately afford the necessities I mentioned above, such as housing, health care and medical expenses, and transportation costs, as well as other incidental necessities that may arise. Also, the U.S. Surgeon General recently proclaimed that there is an epidemic of loneliness and social isolation that affects many disabled and other isolated people, and results in a worsening of health and increases in the occurrence of physical and mental illnesses. State and local agencies need to improve their social case management services.

### Suggested deletions

No response.

## Response 195

## **Reflects Strategic Plan**

I agree with the revised statement.

## Suggested additions

N/A

## Suggested deletions

N/A

## Response 196

## **Reflects Strategic Plan**

I believe this is a positive step in the right direction to remove ableist language from the NIH. This acknowledges an effort to make the mission statement more inclusive and reflective of the wide variety of people who make up the human experience.

### Suggested additions

I think the current proposed language is good.

## Suggested deletions

No response.

Response 197

### **Reflects Strategic Plan**

I prefer the proposed revised mission statement because it resists stigma against disability.

### Suggested additions

No response.

### Suggested deletions

### **Reflects Strategic Plan**

No response.

#### Suggested additions

I suggest revising and simplifying it to: "DISCOVERING BETTER HEALTH"

#### Suggested deletions

No response.

## Response 199

#### **Reflects Strategic Plan**

As a long-time home hospital manager supporting a highly medically complex teenage boy, I believe the wording changes are a step in a better direction.

#### Suggested additions

No response.

#### Suggested deletions

No response.

### Response 200

### **Reflects Strategic Plan**

[Organization redacted] believes that the proposed new mission statement reflects the goals and objectives as outlined.

#### Suggested additions

[Organization redacted] believes that the proposed mission statement is appropriate.

#### Suggested deletions

[Organization redacted] agrees that the language to "reduce illness and disability" should be removed as proposed by the new mission statement.

## Response 201

#### **Reflects Strategic Plan**

No response.

#### Suggested additions

Since there is a greater emphasis on SDOH related to overall health outcomes, how about adding something like this:

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

### Suggested deletions

No response.

# Response 202

## **Reflects Strategic Plan**

The new mission statement reflects the goals/objectives of the strategic plan.

### Suggested additions

Quality of life.

### Suggested deletions

n/a

Response 203

### **Reflects Strategic Plan**

I am in support of the new language proposal as I believe it reflects increased wisdom gained in recent years as to issues of quality of life and the best use of knowledge resources and consideration of the patient in a more targeted manner than the previous (current) language.

#### Suggested additions

N/A

### Suggested deletions

N/A

## Response 204

### **Reflects Strategic Plan**

Yes, it does.

### Suggested additions

I don't know why you removed the "lengthen life" part of the mission statement. I think it should still be included; it's definitely a worthy goal. Otherwise. I like the new one.

#### Suggested deletions

No response.

### Response 205

#### **Reflects Strategic Plan**

Sounds good. To prevent illness, promote good health, and propagate one's unique gifts on the planet! To promote a good-natured disposition and health benefits of medication and meditation benefiting one's mental health taking into account holistic diet methods, Eastern and Western medicines as one deems fit in light of the science.

See above.

## Suggested deletions

"Reducing" illness is perhaps to reductive. The mentally ill can go on to lead fulfilling lives!

## Response 206

### **Reflects Strategic Plan**

The change in wording you are proposing is excellent! The new words are much more meaningful.

### Suggested additions

No response.

### Suggested deletions

No response.

## Response 207

### **Reflects Strategic Plan**

I agree with the change since it is incumbent on the Institute to value all human life. THe previouse mission reading "Reducing . . . disability" can be interpreted to mean that persons with disabilities do not have inherent value from conception until natural death.

### Suggested additions

No response.

### Suggested deletions

No response.

## Response 208

### **Reflects Strategic Plan**

No, I do not think the proposed new mission statement reflects the goals and objectives outlined in the new strategic plan. By removing "disability" from the mission statement, you would be removing language that captures the health impacts from injuries (e.g., mechanical forces that can negatively impact the body). This could have the unintended consequences of narrowing the focus of research at NIH to only focus on the cellular aspects of disease. Please do not do that.

### Suggested additions

If the word "disability" is truly objectionable (which I do not think it is based on the reasonings provided), you could replace "disability" with "injury" as a compromised solution that is fully inclusive.

"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 injury."

### Suggested deletions

See above—you could remove the word "disability" and replace it with "injury."

## Response 209

## **Reflects Strategic Plan**

I am a young man (27) from Kansas. I am a self advocate for people with different needs. I have Down syndrome and a hearing loss and some depression. I like taking out the old language in the mission statement, and I like the fresh new language.

### Suggested additions

No response.

### Suggested deletions

No response.

## Response 210

#### **Reflects Strategic Plan**

As a scientist who studies a disabled population, I agree that the revision reflects the goals and objectives, specifically that of "designing research for everyone." As a person with a disability, the revision makes me feel seen, heard, and respected.

#### Suggested additions

No response.

#### Suggested deletions

No response.

### Response 211

### **Reflects Strategic Plan**

Making things where people is healthy.

### Suggested additions

English

#### Suggested deletions

What can cause people to be more healthy living lifestyles.

## Response 212

### **Reflects Strategic Plan**

No response.

## Suggested deletions

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

# Response 213

## **Reflects Strategic Plan**

Thank you for re-visiting the mission statement.

## Suggested additions

I think this removes the sentiment that can be construed as ableist, but perhaps goes too far in de-emphasizing people with disabilities, thereby rendering them invisible again.

Relatedly, "health" tends to interpreted narrowly to be only about reducing mortality rather than also including quality of life or functioning.

### What about the change in CAPS?

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

### Suggested deletions

No response.

# Response 214

## **Reflects Strategic Plan**

Yes, but if there is a way to clarify that the NIH cares for ALL those presently living with serious illness and wishes to contribute to improving their quality of life, that would be appreciated by all people, especially because a large population in the U.S. are caregivers or family members and their quality of life is affected by the improvements in quality of life and quality of care for those with serious illness and chronic disabilities. Just as a comment for any future policies or plans... when describing diversity and equity, please do NOT exclude the Asian population; the Asian American public and scientific community are well aware of how much they are ignored and not prioritized in policies and funding for decades. How statements, policies, and funding opportunities are crafted sends an indirect message to the public of institutional biases and whether their science and findings should be trusted. This is how it has been for decades; no direct public outcry does not mean there is no issue; for Asian populations, there are cultural differences in expression. Grant reviewers are also not trained and have biases. Asians are a growing group and will be observing the actions of institutions like NIH from the background to make their subsequent decisions of engagement in science, health systems, and contributing to policies.

## Suggested additions

### Suggested deletions

No response.

## Response 215

### **Reflects Strategic Plan**

The proposed new mission statement does not, in my opinion, address/incorporate changes and expansion of national health priorities, frameworks, diversity, equity, inclusion, accessibility. I think including reference to several resources: emergency medical services and trauma system care, National EMS Information System prehospital care data, highway safety resource like the USDOT Equity Transportation Community Explorer, Safe System Approach standards, Social Vulnerability Index, etc.

### Suggested additions

I think adding "public health and safety systems" immediately after "living systems." Add ", response," immediately after "optimize health." Both these revisions would facilitate focus and expand information related to systems that impact living systems. Add "severity of injuries" immediately after "reduce illness."

#### Suggested deletions

None that I can think of.

## Response 216

#### **Reflects Strategic Plan**

No response.

#### Suggested additions

No response.

#### Suggested deletions

I recommend removal of the word "optimize" because it is unattainable: one can always do better.

I also recommend that the original word, "enhance," be kept. This is an attainable goal since we believe in the power of Science to improve things.

## Response 217

#### **Reflects Strategic Plan**

Much improved, uncertain if this will be for all of the USA or is inclusive of the entire world.

#### Suggested additions

No response.

#### Suggested deletions

### **Reflects Strategic Plan**

No response.

#### Suggested additions

"The mission envisions to promote fundamental knowledge about the nature and behavior of living systems and apply the knowledge to optimize health and prevent illness across all the population."

#### Suggested deletions

No response.

## Response 219

### **Reflects Strategic Plan**

No response.

#### Suggested additions

No response.

#### Suggested deletions

Government should work more on preventive aspect of health along with promotive part. We are borned to live naturally with natural foods not synthetic and prservatives or chemicals like benzylperoxide. So, It should focus on herbs, yoga and relevant effective therapies with modern tools and skills. Psychological illness can be eradicated if we could launch meditation camps and ways to remain calm and productive to every community, organization, prison and schools. We have developed enough modern equipments and modalities for diagnosis but not enough safer treatment mechanisms or procedures. Antibiotic resistivity has been over the roof thede days. Shouldnt we look for natural alternatives for these circumstances? We have to look for best possible ways for total knee /hip replacement. There is no ways other than depending on natural sources. We are made up of biochemicals not only chemicals (synthetic). Therefore, For promotion of health awareness is utmost. Spread awareness on metabolic disease and naturak diets, food habits. Healthy diet, healthy mindset (meditation), and healthy work environment is only the solution except for emergency.

## Response 220

### **Reflects Strategic Plan**

Looks good.

#### Suggested additions

Good as is.

### Suggested deletions

None.

### **Reflects Strategic Plan**

No response.

### Suggested additions

I suggest another "in" statement in the section ... "realizing these goals, the NIH provides leadership and direction to programs designed to improve the health of the Nation by conducting and supporting research."

The suggestion follows: "in the causes, diagnosis, prevention, and cure of human diseases."

The suggestion states: "in the causes, diagnosis, treatment, and evaluation of human responses to illness and to health."

Rationale: Without this suggested statement is that nurses diagnose and treat human responses to illness, e.g., silent reactions to rape and other trauma, hypoglycemic reactions, health-seeking behavior, low oxygen saturation. In other words, nurses diagnose and treat a wide spectrum of responses that people exhibit in health and in illness. We have an entire taxonomy of responses. To omit such, is to obviate the contributions of nursing to health and wellness. Furthermore, in the last decade, NIH NINR researchers have found that nursing diagnoses, e.g., coping self-efficacy, is indirectly related to inflammatory biomarkers. As coping self-efficacy increases, inflammatory biomarkers decrease. Coping self-efficacy is a nursing diagnosis, and our research knowledge base includes inflammatory responsivity. Unless the nursing profession's knowledge base is include among the "in" statements, the NIH mission statement will be incomplete and not reflective of the broad expanse of health and illness responsivity in the U.S.

### Suggested deletions

No response.

## Response 222

### **Reflects Strategic Plan**

The discovery of clustered regularly interspaced short palindromic repeats (CRISPR) and the subsequent technology and research into the lengthening of human life with the concentration on youthful vigor for hundreds of years and beyond is here. The first or current mission statement is more comprehensive to ALL people needs to be stated. It should read "To seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, cure and prevent diseases, for all people." CRISPR has already been noted to cure sickle cell anemia, cystic fibrosis, and many other diseases. CRISPR has also regenerated youthful skin in older people. Let us not let greed and covetous behavior deprive humanity of the glories of the knowledge and salubrious products of sciences. The most diverse genetics have the best potential for survival. Let us not restrict the survival of humankind "us" because of greed and selfishness.

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## Suggested deletions

The discovery of clustered regularly interspaced short palindromic repeats (CRISPR) and the subsequent technology and research into the lengthening of human life with the concentration on youthful vigor for hundreds of years and beyond is here. The first or current mission statement is more comprehensive to ALL people needs to be stated. It should read "To seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, cure and prevent diseases, for all people." CRISPR has already been noted to cure sickle cell anemia, cystic fibrosis, and many other diseases. CRISPR has also regenerated youthful skin in older people. Let us not let greed and covetous behavior deprive humanity of the glories of the knowledge and salubrious products of sciences. The most diverse genetics have the best potential for survival. Let us not restrict the survival of humankind "us" because of greed and selfishness.

# Response 223

### **Reflects Strategic Plan**

I believe it does.

### Suggested additions

None, I like the new additions and revisions.

### Suggested deletions

None, I'm very grateful "reduce...disability" was removed. I'm not disabled, but am an Occupational Therapist working in a wellness program supporting people with lifelong disabilities living healthy and vibrant lives.

## Response 224

### **Reflects Strategic Plan**

Yes.

I suggest adding "well-being" after health so that it reads "...to optimize health and wellbeing and...." By including well-being, you can address people who are healthy (not ill) but have needs due to disabilities.

### Suggested deletions

I would remove the word "to" before apply so that it reads: "To seek fundamental knowledge about the nature and behavior of living systems and apply...." Rationale: improves flow and grammar.

## Response 225

## **Reflects Strategic Plan**

Yes. I believe that the proposed new mission statement reflects the goals and objectives as outlined in the NIH-Wide Strategic Plan for Fiscal Years 2021–2025.

### Suggested additions

I would suggest to evaluate possibility of using "wellbeing" instead of "health" to include one's satisfaction about their life. Hence, I would use this form: "To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to optimize health, wellbeing and prevent or reduce illness for all people." Or "To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to optimize wellbeing and prevent or reduce illness for all people."

### Suggested deletions

The reason I think is the wellbeing concept can be added to the mission statement is that it include more aspect of life than those listed in the definition of health. For example: Life satisfaction, Domain specific satisfaction, and Engaging activities and work. Here is the reference link: https://www.cdc.gov/hrqol/wellbeing.htm#two.

# Response 226

### **Reflects Strategic Plan**

Spot on.

### Suggested additions

No response.

### Suggested deletions

The librarian training component is too specific and should be deleted.

## Response 227

### **Reflects Strategic Plan**

"...enhance the quality of life..." should displace "lengthen life...," because a longer life is not a universally desired outcome by individuals or society.

No response.

### Suggested deletions

No response.

## Response 228

## **Reflects Strategic Plan**

I'm the mother of a 13-year-old boy with Down syndrome. I support the revised language and wish more focus could be on research, education, advocacy and awareness than on a mission statement few people will actually read.

### Suggested additions

No response.

### Suggested deletions

No response.

## Response 229

### **Reflects Strategic Plan**

"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."

- 1. Unclear what "optimize health" is supposed to mean.
- 2. Terms are rather vague.

### Suggested additions

Address the need to be clear and specific:

"To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to prevent CHRONIC disease, IMPROVE OVERALL health, and reduce THE BURDEN OF illness for all people."

### Suggested deletions

No response.

## Response 230

### **Reflects Strategic Plan**

This seems to reflect the goals and objectives from the strategic plan, but those could also be improved.

### Suggested additions

To continuously seek fundamental knowledge about the nature, behavior, and interactions of living systems and to apply that knowledge to optimize health and quality of life for all people and communities. "Continuously" underscores the process of scientific inquiry and that we continue to make discoveries. "Interactions" describes the movement towards more

practical trials that acknowledges the interaction of what we study. "Quality of life" encompasses what community members often describe as most important to them—for example, they don't necessarily want to live longer if they're in pain or take medications with embarrassing side effects. "Communities" makes this more inclusive that we're not just trying to improve individual health, but rather entire communities of people living together. These additions reflect what I constantly hear from community members and some researchers about what to strive for, but I'm not sure that it's truly reflected in the strategic plan.

### Suggested deletions

My feedback above about ways to improve the proposed mission statement may not apply because the strategic plan may not actually help work towards these additional goals. In this case, maybe these should be aspirations for a future strategic plan.

## Response 231

## **Reflects Strategic Plan**

To pursue and apply fundamental knowledge about the nature and behavior of living systems to optimize human health and prevent or reduce illness and disability across the lifespan.

### Suggested additions

To pursue and apply fundamental knowledge about the nature and behavior of living systems to optimize human health and prevent or reduce illness and disability across the lifespan.

### Suggested deletions

No response.

## Response 232

### **Reflects Strategic Plan**

The statement fails to capture the efforts of NIH to encourage and inspire a more diverse workforce of researchers.

### Suggested additions

To encourage all 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.

### Suggested deletions

Otherwise good statement.

## Response 233

### **Reflects Strategic Plan**

Why must you wipe out disability altogether? Illness and disability are two different things and not used interchangeably. If your child is born with a developmental disability, it may not mean they have an "illness" but rather had a birth defect—is that an illness? I hope that the NIH is working to prevent disability. That is not a bad thing to do nor does it promote ableism. I haven't polled them all, but logic would say that most people with disabilities would rather not have them. As a mother of a disabled young adult, I hope that research is being conducted and applied so that we can prevent the conditions that caused my son to have an intellectual and developmental disability. This does not mean that we want to wipe out people with disabilities but if we can prevent the causes then we should work toward that.

### Suggested additions

The word DISABILITY should in your mission statement if it is part of your mission. Otherwise, the perception is that it is not part of your mission—it is as simple as that.

### Suggested deletions

To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to optimize health and prevent the causes of illness and disability.

## Response 234

### **Reflects Strategic Plan**

No response.

### Suggested additions

Recommend revised mission statement:

"To seek open fundamental knowledge about the nature and behavior of non-artificial biological matter and to apply that knowledge to optimize well-being and prevent or reduce illness for all people."

### Rationale for changes:

Open: The idea of "fundamental" knowledge is subjectively written by "founders." It is important to leave it open to revisions and questions, especially when they are recognized to be impositional on biological manner.

Non-artificial biological matter: In a world of "artificial intelligence" and genetic engineering, it is important to distinguish human-untainted biological matter from adulterations of them. Well-being: Well-being emphasizes health from all human-relevant concerns.

### Suggested deletions

No response.

## Response 235

### **Reflects Strategic Plan**

Remove the word "fundamental."

It is about all knowledge... fundamental and advanced.

### Suggested additions

"To seek 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."

### Suggested deletions

No response.

# Response 236

## **Reflects Strategic Plan**

It does but could be enhanced.

### Suggested additions

NIH mission is "to pursue a profound understanding of the intricacies and behaviors of living systems and leverage this knowledge to advance health, extend lifespans, and diminish the burden of illness and disability."

### Suggested deletions

No response.

Response 237

## **Reflects Strategic Plan**

Yes.

#### Suggested additions

Optimize seems too technical and not in keeping with the general tone of the statement. I suggest either "improving heatlh" or "advancing health."

### Suggested deletions

Per Word, the Flesch Reading Ease readability score 36.4 and Flesch-Kincaid Grade Level score is 15.1 both indicating college level reading capability.

I have no suggestions to reduce these values; however, this may be an opportunity for inclusion.

### Response 238

#### **Reflects Strategic Plan**

No response.

### Suggested additions

It should be "optimize health AND WELLNESS." We need to ensure physical and mental health are both considered.

#### Suggested deletions

No response.

### Response 239

### **Reflects Strategic Plan**

Yes-New Mission Statement is more concise.

N/A

Suggested deletions

N/A

## Response 240

## **Reflects Strategic Plan**

Your mission will not change over time. It is singular and ongoing. Strip away all the ornamental overthing and you're left with only your purpose for existing: "to improve public health through humane research at the nation's highest level."

### Suggested additions

"The Mission of the National Institutes of Health is to improve public health through humane research at the nation's highest level."

WHY: (1) Less self-conscious language. (2) Adding "humane" acknowledges respect for known and unknown effects of research on subjects like cephalopods. (3) "nation's highest level" positions NIH above the many research orgs extant.

### Suggested deletions

"living systems" is covered by "humane."

"and": mission is a singular word; its organization-specific definition should be singular as well. There may be many strategies to achieve the mission, e.g., "conduct research," but the NIH Mission is the best health for every person.

Minimize HOW the mission is to be accomplished, e.g., research, and recognize that the kinds of health, e.g., illness or prevention, are covered under "health." The most useful mission statements are one short, simple sentence.

Delete well-meaning but extraneous language like "of all people." "Public" IS public.

## Response 241

### **Reflects Strategic Plan**

No response.

#### Suggested additions

Due ot increase in health gaps between and among various races of people, It is imperative that NIH acknowledges and advances a mission to reduce health gaps within marginalized and underserved populations.

### Suggested deletions

### **Reflects Strategic Plan**

Removing the term disability makes it seem like my condition is "normal" and "acceptable." I want to be cured and resent the insinuation that I should just give up in the name of diversity.

Also, keep in mind that not all conditions covered by the NIH (e.g., injuries) are illnesses.

### Suggested additions

No response.

#### Suggested deletions

As someone with a psychological disability that requires me to give up one afternoon and evening every two weeks to keep me functional, out of the hospital, and employed (thank you NIMH ketamine researchers), I am concerned about this trend away from curing disabilities. PLEASE FIX ME. Living with mental illness is not "normal" or something I should "just accept" in the name of diversity. Don't minimize my experience by refusing to acknowledge that my condition is a "burden"; it is a burden and I want scientists to continue to work to reduce that burden.

## Response 243

### **Reflects Strategic Plan**

This new mission statement promotes NIH's goals to assist all persons in their health journey.

### Suggested additions

Language such as "promoting functioning" would shift focus on disease outcomes, which, while important, are often difficult to achieve and don't meet the lived experiences of patients.

#### Suggested deletions

No response.

### Response 244

### **Reflects Strategic Plan**

Yes, with the exception of excluding patients with disabilities and reducing it to illness.

#### Suggested additions

Keep disability in the statement.

### Suggested deletions

## **Reflects Strategic Plan**

[Organization redacted] respectfully 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. Specifically, it removes reference to: "understanding biological, behavioral, and social determinants of population health." Nor is it representative of disorders and burdens due to injuries or many congenital and other chronic conditions that adversely affect the quality of life of millions of Americans.

While we understand that NIH is being responsive to stakeholder input, the proposed change ignores the views of an important group of constituents in the disability community. At a recent NSF-sponsored National Academy of Sciences meeting on Ableism, Dr. Jacqueline Chini addressed language surrounding Ableism, and defined Disability as the "loss of opportunity to take part equally (due to physical or social barriers), as complementary to but different from Impairment (functional limitations)." "Say the Word," she said. She defined Disability as identifying the need for equity, distinct from the negative term disableism, which encourages active discrimination of this growing population of Americans. Participants were encouraged not to shy away from it, and each speaker not only used the term, but readily disclosed their own disability to "build trust, promote relationships" and learn how to identify and communally work to meet the needs of individuals. Many noted how their "disability-identify" had driven their sense of belonging and purpose.

### Suggested additions

1) Do not help stigmatize people with disabilities by removing the term disability from the NIH mission; or

2) "...reduce illness and impairments that limit function and opportunity..."; or

3) "...reduce illness and chronic conditions that limit function and opportunity..."; or

4) "...reduce illness, physical, and mental conditions that limit function and opportunity..."

We appreciate that none of 2–4 are as precise or inclusive as the current NIH mission statement. Disability, as distinct from Illness (vs. Health), covers a wide range of disorders, including trauma, brain and spinal cord injury, and many other conditions, particularly chronic conditions that limit full participation, that must not lose support or priority within the NIH mission. Their costs to individuals and society are immense. The term disability encompasses not only the physical but also the environmental factors within the medical establishment and society at large that contribute to or diminish peoples' quality of life and recovery, where recovery is desired and may potentially be enhanced as a result of the research supported by NIH funding. These barriers, along with underlying impairment of physical structures in organs and the nervous system after damage or other chronic structural conditions unrelated to illness, require active research efforts to be identified and addressed.

## Suggested deletions

"for all people"—Addition of this phrase carries little meaning and, if meant to substitute for disability, or to imply equity, it fails.

More clearly delineating impairment/disability (two different dimensions of function) would make this overly vague phrase, "for all people," unnecessary.

# Response 246

### **Reflects Strategic Plan**

I am a Deaf person, and I don't think of myself as having an "illness," so I am concerned that the statement is lacking reference to barriers we experince—in addition to—illness. I mean inclusive of all of us. I also have MS & that is an illness, so don't get rid of that part.

#### Suggested additions

prevent or reduce barriers and illness for all people. I am Deaf and do not think of myself as having an "illness." I face barrriers of different kinds, which makes daily life functioning difficult but not because I'm "sick," just like a person without legs is not "sick."

#### Suggested deletions

No response.

## Response 247

### **Reflects Strategic Plan**

Maybe.

#### Suggested additions

To seek fundamental knowledge about the nature and behavior of living systems and use that knowledge to enhance health, lengthen life, and reduce illness and disability.

Or

To seek fundamental knowledge about the nature and behavior of living systems and use that knowledge to optimize health, lengthen life, and reduce illness and disability.

### Suggested deletions

Remove the word/variations of the word "apply." Make the the point clear and understandable to scientists and the general population. Everyone understands what it means to "use" knowlege and use is not limited to application. Retaining illness and disability includes a focus on non-illness related conditions. If a goal is to optimize health, the focus shouldn't just be on addressing "illness."

## Response 248

### **Reflects Strategic Plan**

The proposed new mission statement doe not reflect all strategic goals. It does not address the training and mentoring component of advancing science through training scientists, and it does not address the DEIA aspect of making the outcomes accessible to all.

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 seek fundamental knowledge of living systems, to support diverse clinical and scientific workforce training and expand scientific research capacity, advance technologies, treatments and strategies to prevent disease and promote health.

### Suggested deletions

No response.

## Response 249

### **Reflects Strategic Plan**

No response.

## Suggested additions

As a school psychologist who has worked with the general population within public schools across three states for more than thirty years, the proposed revised mission is inadequate and needs to include the enhancement of functioning within occupational and school settings. It's not enough to optimize health and prevent or reduce illness if their functioning is not enhanced enough to be able to work and attend school successful. I urge the NIMH to consider this addition to the proposed revised mission statement.

## Suggested deletions

No response.

## Response 250

## **Reflects Strategic Plan**

The proposed new mission statement DOES NOT reflect the goals and objectives as outlined in the NIH-Wide Strategic Plan for Fiscal Years 2021–2025 as the word "biomedical" is not reflected in it. The proposed revised mission statement does not embody the essence of the goals and 3 objectives as it does not include terms that reflect the mission, goals, and objectives that are: 1. Advancing Biomedical and Behavioral Sciences; 2) Developing, Maintaining, and Renewing Scientific Research Capacity; 3) Exemplifying and Promoting the Highest Level of Scientific Integrity, Public Accountability, and Social Responsibility in the Conduct of Science.

### Suggested additions

Suggestions for specific language that could be added to the proposed mission statement is to choose terms that capture the essence of the 3 objectives and the overall mission. My proposed statement or a modification of it for consideration is:

"To seek fundamental knowledge about the nature and behavior of living systems and to apply that biomedical knowledge to optimize health, foster innovation in research capacity, and prevent or reduce illness for all people for scientific integrity and social accountability in the conduct of science."

Perhaps "fundamental" and "biomedical" could switch places.

"To seek biomedical knowledge about the nature and behavior of living systems and to apply that fundamental knowledge to optimize health, foster innovation in research capacity,

and prevent or reduce illness for all people for scientific integrity and social accountability in the conduct of science."

### Suggested deletions

Nature could be removed. I love the use of the word "ALL." That is inclusivity. Thank you!

# Response 251

### **Reflects Strategic Plan**

I agree that this reflects the goal and objectives of the NIH Strategic Plan.

### Suggested additions

Add in "health service delivery" systems.

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

### Suggested deletions

No response.

## Response 252

### **Reflects Strategic Plan**

EVERY person has physical or mental limitations. Even the fastest, strongest, smartest people in the world can be faster, smarter, or stronger. The concept of ableism being inappropriate discrimination ignores the fact that every person is subject to discrimination relating to their education, experience, and myriad other factors. Removing the word disability from your mission statement will not stop people with disabilities from trying to overcome those disabilities. But it will prevent you from helping them.

### Suggested additions

No response.

### Suggested deletions

No response.

## Response 253

### **Reflects Strategic Plan**

The new mission statement is exceptional.

### Suggested additions

I wouldn't change it, but if you seeking to add a phrase, perhaps "enhance the quality of life as individually defined" at the end. The new statement could read, "To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to optimize health, prevent or reduce illness for all people, and enhance the quality of life as individually defined."

### Suggested deletions

No response.

## Response 254

### **Reflects Strategic Plan**

I think the revised mission statement is more inclusive and is written in more accessible language. I would add an additional sentence to underline the importance of communication of information to public audiences (see box below).

#### Suggested additions

To disseminate factual and accessible information to public audiences, promoting understanding of NIH research and its impact on health and well-being.

#### Suggested deletions

NONE.

## Response 255

#### **Reflects Strategic Plan**

The revised wording is more inclusive and appropriate.

#### Suggested additions

No response.

#### Suggested deletions

No response.

### Response 256

#### **Reflects Strategic Plan**

No response.

#### Suggested additions

No response.

#### Suggested deletions

prevent and reduce illness \*and health inequities\* for all people. Adding something to address health inequities would go a long way here to point out the importance of not only understanding human health and creating more effective treatments etc., but also understanding and addressing inequities that occur due to lack of access to established evidence-based care, as well as inclusion in clinical trials to people in racial and ethnic minorities and people with disabilities to learn more about how effective treatments are in different cultural contexts. I agree that the inclusion of "disability" in the original statement is flawed, as the issue is not to reduce disability, but rather optimize care, address specific needs, and provide opportunities for accessibility for those with disabilities.

### **Reflects Strategic Plan**

I believe the new mission statement supports the goals and objectives and, critically, enshrines direction for future strategic and tactical decisions.

### Suggested additions

No response.

#### Suggested deletions

No response.

## Response 258

### **Reflects Strategic Plan**

I agree with the proposed changes to the mission statement.

#### Suggested additions

No response.

#### Suggested deletions

No response.

## Response 259

### **Reflects Strategic Plan**

It seems to be aligned and is more inclusive than the previous mission statement.

### Suggested additions

No response.

#### Suggested deletions

No response.

### Response 260

### **Reflects Strategic Plan**

No response.

#### Suggested additions

Contribute to human flourishing by alleviating unnecessary suffering and improving overall quality of life from crib to tomb!

#### Suggested deletions

It should be understood as "all people"... so can be removed.

### **Reflects Strategic Plan**

The question is whether the NIH will walk its talk.

"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."

"optimize health and prevent and reduce illness for ALL people" ??? Including diseases that affect many people and produce a high disease burden but which the NIH has a history of neglecting? Such as chronic fatigue syndrome (\$13 million/yr for 2 million people, or fibromyalgia (\$13 million/yr for 10 million people).

Is the NIH committed to supporting ALL diseases according to their needs? Clearly not yet. Time to live up to your mission statement!

#### Suggested additions

"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 equably."

#### Suggested deletions

No response.

## Response 262

### **Reflects Strategic Plan**

No response.

#### Suggested additions

No response.

#### Suggested deletions

Please consider adding "and function" after the word health.

## Response 263

### **Reflects Strategic Plan**

No response.

#### Suggested additions

NIH's current mission statement could be interpreted as perpetuating ableist beliefs that disabled people are flawed and need to be "fixed." I like that the proposed new 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," removes "disability" from the mission statement. However, the purpose of "reducing disability" is to improve function, and that should still be part of the NIH mission. An alternative suggestion for the new mission statement is

"To seek fundamental knowledge about the nature and behavior of living systems and to

apply that knowledge to enhance health, optimize function, and prevent or reduce illness for all people."

### Suggested deletions

No response.

## Response 264

### **Reflects Strategic Plan**

The mission statement is improved and reflects the goals and objective in the NIH strategic plan.

However, the term "fundamental knowledge" could be misconstrued to exclude scientific knowledge generated at later stages in the research translational pathway, e.g., dissemination and implementation (D&I). Yet, D&I research is critical to accelerating the uptake of evidence-based interventions in order to optimize health and prevent or reduce illness for all people. Similarly, the proposed statement adds the term "health," which is often implicitly used to denote the absence of disease, which is in opposition to how many people (including the World Health Organization) define health. It is critical to define these key terms in the NIH mission statement to avoid confusion.

### Suggested additions

Retain the proposed language AND clearly define the key terms "fundamental knowledge" and "health." These definitions are not ancillary, but critical to the meaning of the mission statement. Fundamental knowledge must be defined so that it applies across the translational continuum and beyond mechanistic knowledge. Similarly, health must be defined multi-dimensionally so that the definition acknowledges, people's well-being, function, and capability for health (Fiscella & Epstein, Milbank 2023).

### Suggested deletions

None.

## Response 265

### **Reflects Strategic Plan**

Yes, the proposed revision reflects the goals and objectives outlined in the Strategic Plan for 2021–2025, but misses part of the goal: Understanding Biological, Behavioral, and Social Determinants of Population Health. I suggest below that language be added to more fully acknowledge the NIH's goal to understand behavioral and social determinants of health (and to maintain some reference to functional limitations (disabilities).

### Suggested additions

It is important to maintain some language related to functional limitations (aka, disabilites). Certainly, the idea of "reducing" disability in the existing mission statement is overly simplistic. It does not capture the breadth and depth of existing interventions and research on managing disabling diseases and conditions.

### Here's possible language:

"To seek fundamental knowledge about the nature and behavior of living systems and to

apply that knowledge to enhance health and function, and to prevent or reduce illness for all people."

### Suggested deletions

No suggestions for removing language.

## Response 266

#### **Reflects Strategic Plan**

No response.

#### Suggested additions

I support adding function to the mission, so it would read: To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to enhance health, optimize function and prevent or reduce illness for all people.

This provides a very positive way to balance the decision to remove "reducing disability" from the current mission statement.

#### Suggested deletions

No response.

### Response 267

### **Reflects Strategic Plan**

When disability is removed, it is important to state the positive side by "improving function," the role of rehabilitation.

#### Suggested additions

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

#### Suggested deletions

No response.

## Response 268

#### **Reflects Strategic Plan**

No response.

### Suggested additions

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

The current proposed mission statement implies that we attempt to "fix or reduce" disability per se rather than to optimize function, which is what rehabilitation professionals focus on. We can't eliminate disabilities or fix all disabilities, but we can optimize function.

### Suggested deletions

No response.

## Response 269

## **Reflects Strategic Plan**

No response.

### Suggested additions

I join my colleagues in Physical Therapy to suggest the following:

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

#### Suggested deletions

No response.

Response 270

### **Reflects Strategic Plan**

No response.

### Suggested additions

I would suggest the following that emphasizes function as important reason for seeking knowledge about the nature and behavior of living systems.

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

### Suggested deletions

No response.

## Response 271

### **Reflects Strategic Plan**

Thanks for removing "disability" its been year of stigmatizing me and my healthcare ..and Im also a clinical healthcare provider also currently in research myself hoping to be able to give back and help other people with cancer /hiv/ Appreciate looking at it more positive perspective ..Ive always felt shamed and less then. Trying to return to societal norms like work already have the SSA working against us leaving us trying to figure out how do we do this with dignity and keep disability from not becoming yet another "Illness."

### Suggested additions

No response.

### Suggested deletions

### **Reflects Strategic Plan**

If you're only mentioning all living systems you are leaving out research involving assistive technology.

### Suggested additions

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

### Suggested deletions

Living systems seems very impersonal bit I'm not sure of another word, maybe human beings. Maybe living beings?

## Response 273

### **Reflects Strategic Plan**

The new mission is clear and I think reflects the goals and objectives of the NIH strategic plan.

### Suggested additions

I wonder if there is room to emphasize enablement and/or function within the statement. For example, "optimize health, maximize function, and prevent or reduce illness...." I recognize that physical wellbeing is one of the domains within the definition of "health" and therefore optimizing health would optimize physical well being. However, physical wellbeing does not necessarily include function.

### Suggested deletions

None.

## Response 274

### **Reflects Strategic Plan**

No response.

### Suggested additions

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

### Suggested deletions

No response.

Response 275

### **Reflects Strategic Plan**

I agree with the removal of "disability"; however, it leaves a gaping hole in the mission. I suggest the addition of "optimize function" instead.

### Suggested deletions

No response.

Response 276

## **Reflects Strategic Plan**

No response.

### Suggested additions

Get rid of disabilities and say you want to "enhance abilities."

## Suggested deletions

No response.

## Response 277

### **Reflects Strategic Plan**

Overall the statement is good, but it misses that physical function aspect. It could be revised to state "To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to enhance health, optimize function, and prevent or reduce illness for all people." It might be argued that physical function is part of health but not completely convinced of that as the disability aspect that was in the statement before contained that.

### Suggested additions

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

### Suggested deletions

No response.

## Response 278

### **Reflects Strategic Plan**

The NIH's proposed revised mission statement does not fully reflect the goals and objectives as outlined in the NIH-Wide Strategic Plan because it does not specifically call out the global implications of the work nor the emphasis on the lifesaving innovations made possible by NIH research.

"To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to optimize health and spur innovation for the prevention or reduction of illness for all people in the United States and around the world."

The proposed changes put forward by the [organization redacted] are inclusive of two major themes found in the NIH-Wide Strategy Plan for FY21–25. The NIH sees its research as having a global impact. Not only through its extramural funding but also through the impacts NIH research has had on the global biomedical knowledgebase and innovation landscape. By including the phrases "in the United States and around the world" and "spur innovation" in the mission statement, the NIH would be acknowledging the interconnected nature of the US's premier biomedical research apparatus to the health and well-being of all people. Not to mention, by calling out innovating the NIH will be seen as leaning into the current excitement and potential of bioconvergence.

#### Suggested deletions

No response.

## Response 279

### **Reflects Strategic Plan**

While seeking knowledge is a general aspect of human existence, the goal of the NIH and NIA is to facilitate this process, which is not evident with the current mission statement. The application of the knowledge to promote healthspan, while may not always be possible, but is the overall objective.

### Suggested additions

Below is a modified version of the proposed mission statement with the idea of the specific role NIH/NIA will be playing in seeking the fundamental knowledge, ergo promote.

"To promote inquiry of the fundamental nature and behavior of living systems with the objective to optimize health and prevent or reduce illness for all people."

### Suggested deletions

"and to apply that knowledge"—while all knowledge moves us forward, not all knowledge is translatable to prevent illness or disease.

It is better to say that the "objective" is to optimize health and disease burden. If the objective is at the forefront, then it follows that the knowledge gained will be used to meet that objective.

### Response 280

#### **Reflects Strategic Plan**

NIH mission should be to optimize function and participation, and be consistent with the ICF framework.

To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to enhance health, optimize function and participation for all people.

### Suggested deletions

No response.

## Response 281

## **Reflects Strategic Plan**

Would like to see "function" incorporated to replace the previous wording of "disability."

## Suggested additions

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

### Suggested deletions

No response.

## Response 282

## **Reflects Strategic Plan**

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.

### Suggested additions

So that the alternative suggestion for the new mission statement could be "To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to enhance health, optimize function, and prevent or reduce illness for all people."

### Suggested deletions

No response.

## Response 283

### **Reflects Strategic Plan**

As a physiatrist I would consider adding something about maintaining or recovering function and independence. The concept of disability has been dropped but perhap more positive input would be more appropriate without losing the impact of need to maintiain independence. Without independence we increase costs to thehealthcare system and to individuals. Disabled persons are one of the minority groups most frequently discriminated against and often these people have no advocates to assist them.

To seek fundamental knowledge about the nature and behavior of living systems and apply that knowledge to optimize health, prevent and reduce illness and to promote independent function for al people.

### Suggested deletions

No response.

## Response 284

### **Reflects Strategic Plan**

I don't understand why the NIMH would consider removing as part of their mission, "reducing disability." By definition, disability (as opposed to illness or impairment) is when the built or social environment prevents or diminishes functioning. Having "reducing disability" in the mission statement acknolwedges the chronic nature of many psychiatric and developmental conditions, and the need to develop supports throughout society to allow people with these conditions to live their fullest, richest possible life. I strongly encourage you to add it back in.

### Suggested additions

"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 and disability for all people."

### Suggested deletions

No response.

## Response 285

### **Reflects Strategic Plan**

True it does. Add ..."palliate best what we still cannot prevent or cure."

### Suggested additions

Add ..."palliate best what we still cannot prevent or cure"

As so many waste precious time resources in trying non scientific unproven or proven non scientific means under rights of free choice. For those Research offers relief. Adds better qaulity life to years and years to life.

### Suggested deletions

Research should aid in spreading awareness for Early diagnosis too as much for Preventing an illness or delaying its manifestation.

## Response 286

### **Reflects Strategic Plan**

I do support that more concise language has been used (i.e., to apply knowledge).

I think that disability should be kept in the new wording of the mission statement. I think it is important not to shy away from using the term disability in an effort to break the stigma surrounding disability.

### Suggested deletions

No response.

## Response 287

### **Reflects Strategic Plan**

I support the language in the new proposed statement and I am glad to see that NIH is making this change.

#### Suggested additions

No response.

### Suggested deletions

No response.

## Response 288

### **Reflects Strategic Plan**

I like the idea of removing "disability" but still I think the idea that we need to improve function should be included.

### Suggested additions

Per the prior comment, I like the idea of replacing "reduce... disability" with "improve or optimize function." So it would read: "To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to enhance health, optimize function, and prevent or reduce illness for all people."

### Suggested deletions

No response.

### Response 289

#### **Reflects Strategic Plan**

No response.

### Suggested additions

I think the "prevent or reduce illness" is misleading. Is that all we are looking to prevent or reduce related to health outcome?

What about ending with "to optimize and enhance health for all people."? This is a powerful statement. Adding "prevent or reduce illness" at the end loses the "oomph" of that statement and is misleading with regard to who the NIH is.

### Suggested deletions

As a DEIA practitioner, I would remove the language related to illness because negative outcomes related to health aren't always considered an illness. For instance, health disparities isn't an illness but it is something that we need to address and understand to optimize and enhance health for all. The same for socioeconomic status. And I could go on (e.g., systemic racism). When we start listing things we want to prevent or reduce that are getting in the way of positive health outcomes, illness isn't the only thing we need to consider. By removing it altogether, we are left with a far more inclusive statement from a DEIA perspective.

# Response 290

## **Reflects Strategic Plan**

The proposed mission statement does not address "burden of disease" (within Objective 1 of the strategic plan). This was likely addressed by "reduce disability" in the current mission statement. While the term "disability" is problematic and should be removed, it must be replaced with something to indicate that part of the mission of the NIH is to reduce the burden of the disease on life and society.

## Suggested additions

I suggest either "optimize function" or "optimize health-related quality of life" be added to the statement, as these option encapsulate the nature reducing the burden of a disease on one's daily life. Reducing illness and optimizing health does not imply a focus on optimizing available function and improving quality of life.

## Suggested deletions

No response.

# Response 291

### **Reflects Strategic Plan**

No response.

### Suggested additions

NIH's current mission statement 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."

... The current mission statement could be interpreted as perpetuating ableist beliefs that disabled people are flawed and need to be "fixed."

Considering this, the proposed new mission statement is: "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."

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.

Thus, the alternative suggestion for the new mission statement could be "To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to enhance health, optimize function, and prevent or reduce illness for all people."

#### Suggested deletions

No response.

### Response 292

#### **Reflects Strategic Plan**

Please consider an alternative that emphasizes the importance of function, as well as health.

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

#### Suggested additions

Optimize function.

#### Suggested deletions

No response.

## Response 293

#### **Reflects Strategic Plan**

The current mission statement could be interpreted as perpetuating ableist beliefs that disabled people are flawed and need to be "fixed."

Support the initiative to update the mission statement.

#### Suggested additions

The proposed new mission statement is: "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."

While the decision to remove "disability" from the mission statement is sound, the purpose of "reducing disability" is to improve function.

Therefore, I suggest the following edit

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

#### Suggested deletions

Remove disability. Focus on improving health and function.

### **Reflects Strategic Plan**

The proposed mission statement, when viewed in contrast to the previous one, is at odds with the Strategic Plan's overarching goals of preventing disease and promoting health, and developing and optimizing treatments, interventions, and cures. The impetus for the proposed rephrasing seems to rest either on a confusion of the will to reduce disability with some hypothetical will to eliminate the people affected by disability, or on a confusion of disability with mere difference. About a quarter of people with autism speak few or no words. This lack of speech—and often a complete lack of words—constitutes a frank disability, one that cries out for treatment and, where possible, cure. I voice this observation both as a scientist studying autism and as the brother of a non-speaking, profoundly autistic man. He ought by rights to be the one typing this comment, but because of his disability, he can't. NIH must not abandon its goal of reducing disability!

### Suggested additions

Reducing disability is, fundamentally, about maximizing individual humans' agency within the environments in which they live and work. So, if some parties nevertheless insist on eliminating the words "reduce. . . disability" then perhaps a mutually acceptable substitute would be "maximize agency." This change to the proposed text would leave us with something like "To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to optimize health, prevent or reduce illness, and maximize agency for all people." Ideally, though, the language about reducing disability would be retained.

### Suggested deletions

No response.

## Response 295

#### **Reflects Strategic Plan**

This proposed update appears to fit the NIH Strategic Plan. I like that it is written in a way that's more respectful of those with disabilities.

### Suggested additions

This isn't a suggestion for language to be added, but a plea to avoid large-scale, politically motivated activities and to actually focus on health disparities and chronic illnesses that affect so many people, especially those from underserved communities. Lots of funding goes to the loudest voices, but chronically ill individuals often can't advocate for themselves at the same level. So, if these changes are added to the mission statement, I really hope that they are also implemented in funding decisions and research support.

### Suggested deletions

This seems fine to me. I like the more active way that the update is written. Please do apply money to these issues. It seems like leadership is often distracted by high-profile things and ignores issues affecting URM populations and those with disabilities. We need more funding for health disparities and chronic illnesses, like ME/CFS.

### **Reflects Strategic Plan**

I like the change however it does not really emphasize the need and focus on optimizing function.

### Suggested additions

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

### Suggested deletions

None.

## Response 297

## **Reflects Strategic Plan**

It is insufficient as optimal function is also a key component of quality of life and health.

### Suggested additions

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

This addresses not only health and illness (very medical-model of health) but how people function/interact with their environment. Function can be physical or it can encompass societal and social interactions.

### Suggested deletions

No response.

## Response 298

#### **Reflects Strategic Plan**

No response.

### Suggested additions

I would like to suggest the following wording: "To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to enhance health, optimize function, and prevent or reduce illness for all people."

#### Suggested deletions

No response.

### Response 299

### **Reflects Strategic Plan**

Unsure.

I think you should add "reduce disability" back in. Why would we NOT want to reduce and prevent disability? My son has a significant disability and it does NOT lessen his value as a person. However, if I could magically cure his disability I would! I have a more minor disability but the same thing applies to me—if I could take away my disability I would. By not committing to reduce disability, you might as well say you are OK if more people have disabilities. Why take folic acid during pregnancy if not to reduce spina bifida? Why wear a seatbelt if not to reduce the chance you will be paralyzed? Why try to control diabetes if not to reduce the chance you will end up with amputations or vision problems? Wanting to reduce disabilities in their families. Instead of changing the Mission, work toward reducing the stigma of disability.

# Suggested deletions

NA

# Response 300

# **Reflects Strategic Plan**

No response.

# Suggested additions

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. Without it, the mission statement feels highly medicalized and disregards the importance of individual's ability to function and participate in their environments.

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

# Suggested deletions

No response.

# Response 301

# **Reflects Strategic Plan**

What I like is that the proposed new mission statement doesn't assume the disability is something in the bodies of disabled people that needs to be "reduced." "Illness" is different, because it is (almost) always coded as something negative.

# Suggested additions

No response.

### Suggested deletions

"Optimize" makes me think of bioengineering. It also has a vaguely commercial tinge. Is there another verb that could be used? Improve?

# **Reflects Strategic Plan**

The [organization redacted] supports the proposed revised mission statement for the National Institutes of Health (NIH). This revised statement aligns with the recommendations of the NIH ACDD WGD Subgroup on Individuals with Disabilities, which was largely comprised of researchers with disabilities who have expertise across research fields.

As outlined in this committee's report and recommendations, the current NIH mission statement makes the incorrect ableist assumption that all people with disabilities prefer to be closer to nondisabled. Language directed at the reduction of disability is outdated and promotes unethical interaction between health systems and people with disabilities. While there are people who may want their disabilities removed or eliminated, revising the NIH mission statement to remove the words "reduce... disability" is necessary to promote a more inclusive ethos across the biomedical research enterprise.

The proposed revision to the mission statement also more directly aligns the NIH with recent disability-community driven efforts from HHS. Over the past month, HHS released rulemaking on Section 504 of the Rehabilitation Act that aims to strengthen prohibitions against discrimination on the basis of disability in health care and human service settings. Importantly, this proposed rulemaking clearly frames people with disabilities as a community that faces health disparities and moves away from a myopic focus on eliminating disabilities. Additionally, the NIMHD Director recently designated people with disabilities as a health disparity population, elevating this shifting view around disability within the NIH.

The proposed revision to the NIH mission statement is a welcome and needed change that supports broader adoption of a modern and community-centered framing of disability across the biomedical enterprise.

### Suggested additions

No response.

# Suggested deletions

No response.

# Response 303

# **Reflects Strategic Plan**

No response.

### Suggested additions

I recommend the following modification: "To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to enhance health, optimize function, and prevent or reduce illness for all people." This is a good substitute for the word disability; I believe optimizing function was the original intent of having the word disability in the mission. Optimization of function is key to prevent, reduce and, even, maintain health. Also, it is possible to talk about function optimization without having to stigmatize individuals as health or unhealthy.

# Suggested deletions

No response.

# Response 304

### **Reflects Strategic Plan**

Removing "disability" from the current mission statement is a good step towards reducing ableist beliefs that disabled individuals are "flawed" and need "fixing." However, the proposed mission statement should go a step further to emphasize the ultimate goal of "improving function," regardless of disability status.

### Suggested additions

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

Rationale: enhancing health rather than optimizing it takes out the judgement of what IS optimal health, which is different for different individuals. Optimizing function to be added, since it is the ultimate goal, regardless of health or disability status.

### Suggested deletions

See above.

# Response 305

# **Reflects Strategic Plan**

It does, but the statement could include "equity" to highlight the NIH's commitment to equitable health outcomes for all people.

### Suggested additions

To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to pioneer groundbreaking diagnostics and treatments, inform disease prevention and health promotion strategies, and ensure equitable health outcomes for all people.

The above is longer than what you have proposed, but it encompasses the breadth and depth of research supported by the NIH. "prevent or reduce illness" falls short of capturing that.

### Suggested deletions

No response.

# Response 306

# **Reflects Strategic Plan**

The new mission removes the word "disability," which is a sound decision; however, the purpose for reducing disability is to improve function and there is no mention of function in the new statement.

I suggest the following change: "knowledge to enhance health, optimize function, and prevent or reduce illness."

# Suggested deletions

No response.

# Response 307

### **Reflects Strategic Plan**

Yes. The new mission embraces the key actions for betterment of humanity.

### Suggested additions

None.

### Suggested deletions

None.

# Response 308

### **Reflects Strategic Plan**

Yes it does reflect NIH's goals and objectives.

### Suggested additions

"To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to optimize equitable health, prevention and treatments for all people."

Would like to emphasize EQUITY.

### Suggested deletions

No.

# Response 309

# **Reflects Strategic Plan**

The proposed new mission statement well reflects the goals and objectives.

### Suggested additions

The proposed mission statement is reasonable as is and eliminates explicit ableism.

### Suggested deletions

# **Reflects Strategic Plan**

### Dear Committee members,

I read the viewpoint that was just published in JAMA "Revising NIH's Mission Statement to Remove Ableist Language" which articulated the reasons for the change. The missing component in this viewpoint was the definition of a disabled person. While most of the used examples seemed logical for the change, disabled persons who experienced an injury that could potentially be repaired were not included! For example, people experiencing spinal injury are functionally disabled however, there is ongoing and promising active research aiming to repair their injury and help them regain functional mobility. Another example includes disabled children who regain their ability to hear or even see. The proposed change will also impact researchers engaged in such efforts while submitting a grant application to the NIH since they will not be able to link their application objective with the NIH mission statement. I therefore propose a modified statement—see below.

### Suggested additions

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

### Suggested deletions

No response.

# Response 311

# **Reflects Strategic Plan**

Yes, the proposed changes are consistent with the goals and objectives as outlined in the NIH=Wide strategic plan for the fiscal years 2021–2025.

### Suggested additions

The update language is good, no further suggestion for addition, removal or other edits.

### Suggested deletions

No response.

# Response 312

# **Reflects Strategic Plan**

I think including "reduce...disability" should be included in the mission statement. My son is a C2 quadriplegic, so I am aware of the controversy around the "political correctness" of the "disabled" term. But because disabled people also do not like to be called "patients," instead that they are "people with spinal cord injuries," suggests that they also do not consider themselves to be "unhealthy" or "ill." So it appears that eliminating "disability" from the mission statement eliminates people with disabilities. Disability is not an "illness."

### Suggested additions

Include "treating disabilities" in the mission statement.

# Suggested deletions

No response.

# Response 313

# **Reflects Strategic Plan**

I believe the NIH mission should include disability. There are people in this world who are disabled and want to be cured. I was born with a defect that affects my quality of life. If there was a procedure out there that could cure my disability I would want it. As of right now most procedures that may help have a 80% success rate. I want something closer to 90%, I mean this is my life we are talking about. Because I am disabled doesn't mean I'm less then, it just means I carry a burden that I want cured. My issue is a physical issue not and illness, with your new definition it feels like the world will stop looking for a way to cure my disability. Please I beg you don't let that happen.

### Suggested additions

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.

### Suggested deletions

I don't think anything should be removed. BUT I do believe that not including disability is not only wrong but does a disservice to the millions of individuals that are struggling with a disability. By excluding "disability" from your mission statement you are dismissing a community of people who want better quality of life.

# Response 314

# **Reflects Strategic Plan**

Please stick with your original language. Do not water it down by using "weasel wording" like "optimize health." I would venture that the vast majority of people who have their range of physical activity limited by a condition that could be alleviated by a medical treatment would want to be able to choose a cure rather than maintain their limited activity. Do not cave to activist groups that want to block continued research into what could be life enhancing care. Give people options.

### Suggested additions

No response.

### Suggested deletions

No response.

# Response 315

# **Reflects Strategic Plan**

Do not change the statement—reducing disability is a worthy goal. Individuals can choose whether or not they would like to seek medical care, but it absolutely needs to be an option! For example, now parents seeking help with children with autism are being told to accept it

versus engage in therapy to allow their children to live a more normal life. This is one of many examples—a teen in our community was punched in the head, which resulted in a brain bleed and almost dying. With ample therapy, he is learning to re-walk, re-talk, and gain his life back (he just graduated from high school and headed to Emory). Maybe he will never be back on that track, but he does not need to lead a disabled life where he can't do anything for himself and has the right to treatment.

# Suggested additions

No change. Per comments above.

### **Suggested deletions**

No change, comments above.

# Response 316

### **Reflects Strategic Plan**

Keep the current mission statement and get these woke, non-sensical ideas out of medicine. I have two disabilities. Avoiding the name doesnt change my reality. The best thing medicine and NIH could do for me is cure my speech and heart disabilities.

### Suggested additions

Keep current statement.

#### Suggested deletions

No response.

# Response 317

### **Reflects Strategic Plan**

No. Removing the word "disability" does not, in my opinion, reflect what the goals and objectives of the NIH should be.

### Suggested additions

Keep the mission statement as it is currently written.

### Suggested deletions

No response.

### Response 318

### **Reflects Strategic Plan**

Ableist beliefs? [What] is wrong with you people? Collectively, how many years of University did the committee that made this recommendation have? Yet they still don't have enough common sense.

#### Suggested additions

And disability.

# Suggested deletions

No response.

Response 319

# **Reflects Strategic Plan**

No.

# Suggested additions

Reducing disability is a good thing.

# Suggested deletions

No response.

Response 320

# **Reflects Strategic Plan**

I believe that many people with disabilities would want them removed, though some (I believe a minority) would not. By changing this langauge, you are ignoring the first group of people. Your goal as a government agency is to serve all citizens.

# Suggested additions

"to optimize health and prevent or reduce illness and disability for those so inclined." (Why, see above—many people would like help with their disabilities).

# Suggested deletions

No response.

# Response 321

# **Reflects Strategic Plan**

It does not. Disabilities are not identities and should be reduced or cured.

# Suggested additions

None.

# Suggested deletions

None.

# Response 322

# **Reflects Strategic Plan**

Forget the proposed alteration in the mission statement. The idea behind it is silly. A disability,

or lack thereof, had nothing to do with the self-worth of an individual. If an individual with a disability does not want conversion to "ability," fine. He or she is free to choose. Please don't do something stupid like this.

Keep the current mission statement.

# Suggested deletions

No response.

# Response 323

# **Reflects Strategic Plan**

I have no comment on this topic.

# Suggested additions

The mission statement should be left unchanged. People who wish to retain their disabilities are free to do so. This is a luxury of wealthy societies that enable the disabled to participate productively. I don't think you will find many people in poor societies that would object to healing their disabilities. When the current fad for viewing the world in terms of power structures and "isms" fades, and we return to a culture of compassion, you would rue the proposed change to your mission statement.

# Suggested deletions

The mission statement should be left unchanged in its prior form: "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." Don't waste time fixing something that is not broken.

# Response 324

# **Reflects Strategic Plan**

The existing mission statement is quite clear, appropriate and on target. I am very opposed to this change, as you devote limited precious resources not to improve health, but to cow yourself and others into a political orthodoxy that values how things are said over what is actually accomplished.

### Suggested additions

MAKE NO CHANGES.

### Suggested deletions

No response.

# Response 325

# **Reflects Strategic Plan**

It does not. One of the objectives of the NIH in the 21–25 strategic plan (as well as in prior years) is to be a "good steward of public funds." I hesitate to guess how much funding is required to seek public comment and respond to a completely unnecessary change in the mission statement, but I know the number is not zero.

None.

# **Suggested deletions**

The existing mission statement needs no alteration. It is clear, concise, and captures the laudable goals of the NIH (and has since adoption). The unnecessary redrafting, and process, of changing said statement detracts from the execution of the work underlying the mission, which is what is actually important.

# Response 326

# **Reflects Strategic Plan**

As someone who has a serious mental illness I find it a great disservice to myself and those like me with a mental illness because this verbage makes me into an ill person instead of a person who has a disability. I am not sick but something is definitely going on in me that makes it very difficult to do the things others take for granted. I don't want my treatment to degrade simply because a doctor someday decides to shrug his shoulders and say he doesn't want to be called an ableist by treating my mental illness.

# Suggested additions

Replace the final phrase with "and reduce or remove the impact of illness and disabilities for all people." This is a realistic statement that reinforces anyone may become impacted by an illness or disability and society is standing by them to help them live the best life possible.

# Suggested deletions

Remove the final phrase "to optimize health and prevent or reduce illness for all people." This phrase erases the possibility that someone may have a disability that inhibits their ability to move through this life in the way that is possible for it to be improved. Instead for me to have a disability it means I don't have a disability and therefore nothing needs to be done to help me.

# Response 327

# **Reflects Strategic Plan**

If you must temper your words to destignatize disability, then you need to find new ways to express the goal to reduce the effects of physical impairment. The majority of those with physical impediments to a fulfilled life, do not consider that "disability" an identity marker. No more than a person with a cold identifies as a cold-haver—most people with impaired mobility, vision, hearing, etc. would welcome any advancement to medicine that could reduce the ways their impairment prohibits their ability to thrive. You MUST acknowledge this. I appreciate adding the goal to 'prevent' illness—but to ignore our aim to prevent disability is a grave disservice to the people our country should be supporting.

# Suggested additions

Reduce illness 'and the negative effects of physical impairment' for all people.

# Suggested deletions

# **Reflects Strategic Plan**

Main the current mission statement and do not adopt the proposed revision, which is more ambiguous.

# Suggested additions

None.

### Suggested deletions

None.

# Response 329

# **Reflects Strategic Plan**

No response.

### Suggested additions

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.

So that the alternative suggestion for the new mission statement could be "To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to enhance health, optimize function, and prevent or reduce illness for all people."

### Suggested deletions

No response.

# Response 330

# **Reflects Strategic Plan**

I do not think the proposed change is correct.

### Suggested additions

I think the current mission statement should be retained as is with no changes.

### Suggested deletions

I think the current mission statement should be retained as is with no changes.

# Response 331

### **Reflects Strategic Plan**

This is silly and the statement should not be changed. The mission of the NIH should be to improve people's health and quality of life.

Please leave as it is.

# Suggested deletions

Please leave as it is.

# Response 332

### **Reflects Strategic Plan**

This seems like a silly waste of time to me.

### Suggested additions

I think striving to enhance the lives of people with disabilities is a noble goal and should be included in the mission statement.

### Suggested deletions

No response.

# Response 333

### **Reflects Strategic Plan**

Please do not change the language to eliminate mention of disability. The proposed change is Orwellian thought control based on the assumption that words control reality rather than describing it. Disabilities are real, and if possible we should cure or heal them for those who wish it. There may be some, such as some members of the deaf community, who would prefer not to have their disabilities rectified if possible, and their wishes should be respected in consultation with their own doctors and health care providers. But the implication that there is nothing wrong with disability per se is false and pernicious.

Please do not use tech-derived or engineering language such as "optimize" when describing the goals of medical research. Humans are not engineering systems to be tinkered with, but living beings. Please use language that reflects the reality of human personhood. "Enhance" is more appropriate and human than "optimize." It would be even better to use the simple verb "heal."

### Suggested additions

"To seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, reduce illness, and alleviate disability."

### Even better:

"To seek fundamental biological, physiological, and psychiatric knowledge and to apply that knowledge to heal the sick, bring respite to the disturbed in mind, help the disabled, and restore and sustain well-being for all people."

### Suggested deletions

# **Reflects Strategic Plan**

The proposed new mission statement must include the word "disability."

### Suggested additions

The original mission statement, or a revised statement that includes the word "disability."

### Suggested deletions

Preventing and curing disabilities is not ableist or wrong. Americans with disabilities and their families need to know that the NIH is putting its full support behind them and is not minimizing their hardships or suffering in an attempt to appease a minority population who enjoy playing word games.

# Response 335

### **Reflects Strategic Plan**

Why did you take out "disability" and the "lengthen life"?? Why wouldn't you want to prevent or reduce disability? Why wouldn't you want to lengthen life? Isnt this the purpose of science and medicine?

### Suggested additions

You could say—to optimize health, and lengthen lifespans by preventing or reducing illness and disability for all "interested" people.

### Suggested deletions

No response.

# Response 336

### **Reflects Strategic Plan**

Dear NIH,

I have a disability. I acknowledge it and so does our government. I would prefer not to have it. Are you suggesting with this new mission statement that doctors, engineers and other health care professionals should not be encouraged nor attempt to help find a solution to my disability? You are flawed and evidently there exist very cruel, sadistic and sinister individuals in your organization who would feel the change is necessary. No change is needed. Please continue to acknowledge my disability, I don't mind, why do you?

### Suggested additions

No response.

### Suggested deletions

# **Reflects Strategic Plan**

DO NOT CHANGE THE MISSION STATEMENT.

There is nothing wrong with the current mission statement—unless you are seeking to pander to the woke mob.

### Suggested additions

No response.

### Suggested deletions

No response.

# Response 338

# **Reflects Strategic Plan**

To the extent the mission statement reduces emphasis on and effort toward finding and implementing curative therapies for any human suffering or physical inconvenience, such a change is counterproductive and misstates what should be the fundamental mission of all medicine—to end or mitigate human biologic component failures. The notion of "ableism" where the concern is that somehow curing ills and disabilities is harmful to the community of the disabled is ridiculous. First and foremost, the disabled are themselves possessed of agency and can seek or refuse treatment. I add that I believe it is evil to suggest withholding treatment for any malady for which there is therapy available and for which the afflicted wish a cure.

The NIH specifically should reject "ableism" because it implies that available care be withheld because a population of most likely healthy people think they know best what is needed for the afflicted.

### Suggested additions

No response.

### Suggested deletions

No response.

# Response 339

### **Reflects Strategic Plan**

No response.

### Suggested additions

I suggest that the proposed language be rejected in full and that the current mission statement be retained.

# Suggested deletions

I am disabled. I have a type of muscular dystrophy, FSHD, that has degraded muscle strength in my arms, legs, and core and resulted in a number of falls, leading to my need to use a wheelchair. There is no treatment or cure for FSHD. The proposed change in language in 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.

I realize that the proponents of the change believe that by stating part of its mission is to lessen disability, NIH may be subtly implying the disabled aren't entitled to the same dignity and respect as those who are not disabled. As someone who is disabled, I don't see it this way at all. I am entitled to full respect, and I want a cure for the genetic defect that causes my disability. I don't feel any less a human being by NIH stating it is working to cure my disease. What offends and worries me is that you are implying by this change in language that you no longer care about finding a cure for FSHD.

# Response 340

# **Reflects Strategic Plan**

Disability means the inability to perform some function or engage in some activity that others can perform or engage in. As such, reduction of disabilities is a good thing. Obviously there are disabililities that cannot be prevented and in many cases persons experiencing them have been able to accomodate and thrive. But the prevention of disabilities, whether congenital or acquired is, overall, worthwhile. If the NIH is not interested in reducing disability, why is it interested in reducing disease or trauma?

I also note the proposed mission statement removes "lengthen life." While I acknowledge that prolongation of life is not always desirable, I would hate to see NIH move in the direction of Canada's MAiD initiative.

# Suggested additions

To seek fundamental knowledge about the nature and behaviour of living systems and to apply that knowledge to optimize health for all people.

# Suggested deletions

No response.

# Response 341

# **Reflects Strategic Plan**

The [organization redacted] community generally agreed that the changes proposed to the NIH mission statement are reasonable and reflect the goals and objectives of NIH's strategic plan. We felt that the revised mission statement both better encapsulates the intended goals and is more inclusive. One noted that the revised mission statement is an improvement as it does not assume that there is a societal goal to prevent disability, which marginalizes those with disabilities and runs counter to knowledge and translation that saves lives and in doing so increases the prevalence of disability.

Several members of the [organization redacted] community suggested additional language to clarify some elements of the revised mission statement. Ensuring that equity is reinforced in the revised mission statement was a major focus of the feedback. One suggestion was to add the word "equitably" to the end of the statement (i.e., "prevent or reduce illness for all people equitably."). While the word "all" implies that public health will take care of everyone, that may not guarantee that everyone will receive the same benefits. The [organization redacted] community felt it was important to clarify that the mission is to ensure that knowledge is equitably sought and applied.

Further, some suggested including the word "wellbeing" in the revised mission statement (i.e., "to optimize health and wellbeing."). They noted that people can have a disease and still be "healthy," and that those with chronic illnesses find terminology like "disease reduction" disparaging as it suggests that something is wrong with them. "Feeling well" is a more subjective but still measurable construct.

Lastly, multiple individuals highlighted the importance of acknowledging the surrounding environment when mentioning "living systems." Because human health is so interconnected with the environment, factors like ecological degradation and climate change have a significant impact. One suggestion was to clarify the "nature and behavior of living systems" language by rephrasing it as "the structure and function of both ecological and biological systems." Another suggestion was to add "within their environments" to the mission statement (i.e., "the nature and behavior of living systems within their environments.").

# Suggested deletions

Some feedback from the [organization redacted] community suggested removing or replacing certain words in the revised mission statement. One suggestion was to remove the word "optimize," potentially replacing it with language around "attaining full health potential."

Another suggestion was to eliminate "and prevent or reduce illness." This was specifically related to the feedback about including the word "wellbeing" and avoiding language around disease reduction that can be offensive to the chronic illness community.

# Response 342

# **Reflects Strategic Plan**

I believe that the mission of the NIH should be to reduce illness and disability. That does not mean that I believe that disability individuals are flawed and must be fixed, it means that I believe that if someone has an what they consider to be an impairment that they wish to improve, that opportunity should be available to them. It's not a decision that should be made by an activist party. I hope that the impact of this change in language is not to remove opportunities for those with disabilities to access treatments or therapies that may mitigate or improve their quality of life if they wish to avail themselves of those opportunities. While some may feel that they do not wish to take advantage of knowledge to "reduce...disability," others may be of a different opinion, which is just as valid for them as an individual.

No response.

# Suggested deletions

No response.

# Response 343

# **Reflects Strategic Plan**

I am certainly nowhere.

### Suggested additions

None needed.

# Suggested deletions

I like the use of the word "humankind" for the ending of the proposed mission statement. It's used in your strategic plan. It's more inspiring and uplifting! It may be old-fashioned, but it's better. I prefer it, as opposed to the more pedantic, well-worn phrase "all people."

# Response 344

### **Reflects Strategic Plan**

I don't think you should remove the term disability from your definition. To remove it would suggest that you are only focused on preventing and reducing Illness and NOT disability— and that you no longer care about addressing disabilities. I hope that is not true. With autism on the rise, 1 in 36 children in the US per recent information on this topic, I am astonished by the fact that you would even consider removing "disability" from a mission statement that identifies what you are trying to prevent and reduce. I have three very close friends with severely autistic kids, and all of them worry about who will care for their autistic children and how they will survive when they (the parents) die. I know there is a current claim that treating disabilities is "ableism," but this is both a newly minted term and a view held in large part by people who are not struggling with disabilities themselves or caring for people with disabilities. I know zero disabled people who are worried more about "ableism" (likewise for their caretakers) than in finding a way to limit the life-altering impact(s) of their disability on their life. Unless the majority of disabled people advise you that they no longer want your research dollars or your attention, you should not be excluding them from your mission statement.

# Suggested additions

I like your current mission statement so do not see why you are changing it. The new one looks like you are shifting your focus away from helping people with disabilities.

# Suggested deletions

# **Reflects Strategic Plan**

Way off the mark!

# Suggested additions

How about being honest and upfront; refer to disabled people as disabled!

# Suggested deletions

Stop the woke nonsense. For heaven's sake you're all beyond help. Stop softening language to the point it becomes meaningless. Disabled people are disabled. It's not Ageism to use the term. It is insulting to treat folks as too fragile and needing some Orwellian correction!

# Response 346

# **Reflects Strategic Plan**

I, personally, would like to be treated by a doctor who doesn't view disability as an acceptable outcome. Doctors who feel differently should not be licensed to practice. We can support and respect people who are disabled without this lunacy.

What's next, don't wear a helmet while bicycling for fear of being disrespectful to people with traumatic brain injuries?

# Language that could be added to the statement

No changes. Leave it as is.

# Suggested deletions

No changes. Leave it as is.

# Response 347

# **Reflects Strategic Plan**

No response.

# Suggested additions

It should read:

To expand knowledge about the nature and behavior of living systems and to apply that knowledge to maximize human health/function and reduce/eliminate anything that compromises it.

# Suggested deletions

Focus on the prize. Avoid playing games with language to propitiate this or that group.

# Response 348

# **Reflects Strategic Plan**

Curing blindness, deafness, and other disabilities should be an explicit part of the mission statement, since that has not been dropped as an NIH goal.

Put back "disabilities" explicitly. The disabled are a marginalized group, and not naming them is to ignore most of them, in favor of a seemingly ableist attitude that denies the disabled special recognition and help.

# Suggested deletions

No response.

Response 349

### **Reflects Strategic Plan**

No response.

# Suggested additions

Add back the language that states the goal is to reduce disability. Unless you no longer plan to fund any research having to do with helping the disabled? Which would be a tragic error.

### Suggested deletions

No response.

# Response 350

# **Reflects Strategic Plan**

The original mission statement accomplishes NIH-WSP 2021-25.

### SHOULD REMAIN UNCHANGED.

### Suggested additions

n/a

### Suggested deletions

Unnecessary to alter original mission statement.

# Response 351

### **Reflects Strategic Plan**

No response.

### Suggested additions

Leave the mission statement alone. The ideology behind this proposed change is true insanity and will not stand the test of time.

### Suggested deletions

# **Reflects Strategic Plan**

I believe the proposed, new mission statement lacks the fullness of the current mission statement.

# Suggested additions

One definition of "disability" is "A disadvantage or deficiency, especially a physical or mental impairment that interferes with or prevents normal achievement in a particular area." If medical science can reduce or eliminate a disability then people should have a choice to make use of that science. Therefore, the U.S. taxpayer funded NIH should make at least some effort to reduce disability when appropriate. As a parent of a disabled child, I ask that you retain language similar to the current mission statement.

### Suggested deletions

No response.

# Response 353

### **Reflects Strategic Plan**

I oppose the change. The new language is simple silly. Were I to develop a disability I would definitely want the NIH to help me reduce it. This language change may discourage research and treatments for disability. It is also clearly pandering to a tiny minority of loud activists. It is not a helpful or constructive change. Thank you.

### Suggested additions

No response.

# Suggested deletions

No response.

# Response 354

# **Reflects Strategic Plan**

I see no fundamental difference between illness and disability in terms of health. Health care that can restore a desired ability to a person that lacks that ability is valid and should be included in the mission. It is possible that some few persons could have an illness that they desire to retain, but that should not stop health care from developing cures that benefit the vast majority that would prefer to be rid of illness. I also see no reason to remove "Lengthen life" from the mission.

### Suggested additions

Restore lengthen life. Restore and disability. Longer life and robust ability are desirable goals for all healthy people.

# Suggested deletions

# **Reflects Strategic Plan**

No response.

### Suggested additions

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

As a physician (Physical Medicine and Rehabilitation), researcher, administrator, and advocate, I appreciate the concerns being addressed about ableism. Nevertheless, it is incredibly important that the mission of the NIH also continue to embrace the principles of improving function and capacity. My proposed addition of the one notion, FUNCTION, would not promote ableism, but it would reflect the current positive aspects that all individuals would benefit from.

### Suggested deletions

No response.

# Response 356

### **Reflects Strategic Plan**

It does.

### Suggested additions

I'm writing to counter those who say disability is not a problem. If people have learned to love and live with their disabilities, I'm very happy for them. But "should we not cure Alzheimer's because it's ableist to want to be able to think and have clear cognition? Is it ableist to want to have a heart that enables you to walk up a flight of stairs?"

The ableist argument is completely utterly and totally ludicrous. Do not allow it to change how you think about curable disabilities.

### Suggested deletions

None. You don't need to change.

# Response 357

### **Reflects Strategic Plan**

I am currently using hearing aids as a direct result of having flown helicopters in the Navy in the 1970's. I would LOVE IT if y'all could find a way to restore my hearing!

So I see NO NEED to change the original statement. There is no need for a new mission statement.

### Suggested additions

Include language that reflects reducing disability.

A statement should be added that recommends that individuals are not required to take advantage of procedures or drugs that reduce or eliminate their personal disabilities.

# Suggested deletions

Anything that suggests that reducing disability is a problem.

# Response 358

# **Reflects Strategic Plan**

To the extent the mission statement reduces emphasis on and effort toward finding and implementing curative therapies for any human suffering or physical inconvenience, such a change is counterproductive and misstates what should be the fundamental mission of all medicine—to end or mitigate human biologic component failures. The notion of "ableism" where the concern is that somehow curing ills and disabilities is harmful to the community of the disabled is ridiculous. First and foremost, the disabled are themselves possessed of agency and can seek or refuse treatment. I add that I believe it is evil to suggest withholding treatment for any malady for which there is therapy available and for which the afflicted wish a cure.

The NIH specifically should reject "ableism" because it implies that available care be withheld because a population of most likely healthy people think they know best what is needed for the afflicted.

### Suggested additions

To the extent the mission statement reduces emphasis on and effort toward finding and implementing curative therapies for any human suffering or physical inconvenience, such a change is counterproductive and misstates what should be the fundamental mission of all medicine—to end or mitigate human biologic component failures. The notion of "ableism" where the concern is that somehow curing ills and disabilities is harmful to the community of the disabled is ridiculous. First and foremost, the disabled are themselves possessed of agency and can seek or refuse treatment. I add that I believe it is evil to suggest withholding treatment for any malady for which there is therapy available and for which the afflicted wish a cure.

The NIH specifically should reject "ableism" because it implies that available care be withheld because a population of most likely healthy people think they know best what is needed for the afflicted.

# Suggested deletions

To the extent the mission statement reduces emphasis on and effort toward finding and implementing curative therapies for any human suffering or physical inconvenience, such a change is counterproductive and misstates what should be the fundamental mission of all medicine—to end or mitigate human biologic component failures. The notion of "ableism" where the concern is that somehow curing ills and disabilities is harmful to the community of the disabled is ridiculous. First and foremost, the disabled are themselves possessed of agency and can seek or refuse treatment. I add that I believe it is evil to suggest withholding treatment for any malady for which there is therapy available and for which the afflicted wish a cure. The NIH specifically should reject "ableism" because it implies that available care be withheld because a population of most likely healthy people think they know best what is needed for the afflicted.

# Response 359

# **Reflects Strategic Plan**

The new mission statement does more harm than good. All disability should be eliminated for that is your job and to think otherwise is breaking of the Hippocratic Oath that you took. It is as if you are saying it is better to be blind or deaf than being able to see or hear.

# Suggested additions

Put disability back in the mission statement. Disability is a medical problem that should be corrected to fulfil any mission statement otherwise it is breaking of your Hippocratic Oath.

### Suggested deletions

Restore the original mission statement for the proposed mission statement breaks your Hippocratic Oath.

# Response 360

### **Reflects Strategic Plan**

The new guidelines do not live up to the stated objectives. Stick with the old guidelines.

### Suggested additions

No response.

### Suggested deletions

No response.

# Response 361

### **Reflects Strategic Plan**

The change to the mission statement is a mistake and will drastically weaken and corrupt your mission. You should keep the original.

### Suggested additions

No response.

### Suggested deletions

No response.

# Response 362

### **Reflects Strategic Plan**

As the mother of a disabled child, I am shocked and disgusted that you are even considering this change. How can you turn your back on people who want help? If some

people choose to keep their disabilities, that's up to them, but it's wrong for them to try to prevent others from choosing assistance. Who are they to harm my child?

### Suggested additions

No response.

### Suggested deletions

No response.

# Response 363

### **Reflects Strategic Plan**

It's not a bad statement, but I think the stated reasoning is suspect. You're scientists, not activists—you're allowed to use "disability" in its literal meaning, as in "a thing that removes one's ability." And those are bad, pretty much by definition.

You should not be apologizing for your efforts to increase people's abilities. If a specific person doesn't consider a specific condition to actually be a disability, that's fine—they don't need treatment if they don't feel anything is wrong. Nobody is going to tell a blind person that they \*must\* get their sight back—it'll just be an option that they have available. And giving them more options is a good and noble thing to do. Stand proud of your efforts there, don't be ashamed of them.

Also, I prefer the "to apply" phrasing over "the application of" phrasing, because it flows a lot more naturally. Please keep that part.

### Suggested additions

Aside from the "disability" discussion above, I really feel like there should be a comma before "and." I'm not sure if that's truly proper grammar, but the sentence is long, and it needs something to break it up a bit.

### Suggested deletions

Can't think of anything.

# Response 364

### **Reflects Strategic Plan**

No, the proposed changes do not reflect the goal.

### Suggested additions

The wording of "reducing disability" should be kept, as it is one of the fundamental goals of medical research and a key to improving many people's lives.

### Suggested deletions

# **Reflects Strategic Plan**

As a physical therapist and health educator, I'm concerned that this statement does not address another determinant of health, function.

Poor function contributes to development of diseases such as diabetes, heart disease, and length of life.

### Suggested additions

"to optimize health, FUNCTION, and prevent and reduce illness"

The present statement seems disease focused. Optimal health demands optimal function to prevent or reduce illness even in a wellness state. It should not be omitted.

### Suggested deletions

None

# Response 366

### **Reflects Strategic Plan**

New mission statement needs to include "disabilities."

### Suggested additions

"To ...or of living systems and to apply that knowledge to optimize health and prevent or reduce illness... and disabilities... for all people."

Those with disabilities have no voice and must be included to receive the attention needed to reduce suffering.

### Suggested deletions

No response.

# Response 367

# **Reflects Strategic Plan**

This us a ridiculous proposal. I have yet to encounter patients that enjoy their disability. The NIH needs to stop trying to appease radical leftwing sensibilities before it loses what remaining credibility it has. Seriously, in medicine we have to feel bad about cursing disabilities now? Hard pass.

### Suggested additions

No response.

### Suggested deletions

# **Reflects Strategic Plan**

I believe the proposed revised mission statement reflects the goals and objectives as outlined by the NIH link above.

### Suggested additions

None.

### Suggested deletions

None.

# Response 369

# **Reflects Strategic Plan**

No, the new mission does not adequately reflect the goals.

### Suggested additions

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

### Suggested deletions

N/a

# Response 370

# **Reflects Strategic Plan**

Agree there are many "disabilities" that do not seek or require cures, including mine. However, a great many still do and there should be middle-ground language which retains visibility for those which truly need a cure. We need to evolve the language.

### Suggested additions

"Prevent or reduce illness and life-threatening disability"

### Suggested deletions

No response.

# Response 371

### **Reflects Strategic Plan**

This is just an excuse to cut costs. Much cheaper for you to just pretend disabilities are just healthy variations. While of course, all you rich people will continue to get the treatments.

### Suggested additions

No change.

# Suggested deletions

No change.

# Response 372

### **Reflects Strategic Plan**

The activists who pressured NIH into updating its language about disability DO NOT SPEAK FOR ME. 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. I am honestly outraged that the NIH is considering removing "to reduce disability" from its mission statement. It feels like a total betrayal.

### Suggested additions

The original language was perfectly fine (except for the lack of grammatical parallelism). I would propose "To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to enhance health, lengthen life, and reduce illness and disability."

### Suggested deletions

No response.

# Response 373

### **Reflects Strategic Plan**

Thank you for this updated language. Disability is natural and we should not seek to "reduce disability" but "optimize health."

### Suggested additions

No response.

### Suggested deletions

No response.

# Response 374

### **Reflects Strategic Plan**

The proposed new mission statement states NIH's goals and objectives more clearly and more concisely and so thereby successfully declares their message of better health for all. NIH's new mission statement format ensures that a diverse population can fully understand their mission statement.

### Suggested additions

# Suggested deletions

No response.

# Response 375

# **Reflects Strategic Plan**

This proposal rests on a clear logical fallacy: it conflates "disability" with "individuals who have disabilities." Disability itself is not a neutral state of identity; by its very nature it means impairment, dysfunction, and incapacity. This fact is mutually exclusive from the other fact at hand: individuals with disabilities have value and should not be stigmatized.

It should go without saying that the goal of reducing disability, i.e., impairment, on both a population and individual level is a moral and pragmatic imperative that does not carry any animus toward individual people whose functioning is limited by their disabilities. Our collective desire to eradicate polio hardly demeans those individuals who have fallen victim to polio-caused paralysis. Our aim to reduce fetal alcohol spectrum disorder, and all the disability it can entail, does not mean we believe those affected are morally flawed, or flawed in the sense of any abstract philosophies. Wanting to reduce these and countless other impairments that reduce functioning and human potential—multiple sclerosis, ALS, schizophrenia, the list is long—hardly equates to "ableism."

When an obstetrician unwraps an umbilical cord choking a neonate, and therefore reducing the risk of lifelong impairment, is she engaging in ableism, or rather the most honorable sort of humanity? By any reasonable standard, disability should be prevented whenever possible. Laws mandating helmets and seat belts are not "ableist"; they protect the public from preventable injury and consequent disability and all the costs, burdens, pains and dependencies that result. When a pregnant woman takes folic acid supplements to reduce risk of spina bifida in her child, she is not "ableist," she is obviously taking prudent preventive measures to reduce the risk of serious impairment in her child. Countless public health campaigns and NIH efforts shine a light on the risks of smoking, to reduce the prevalence of disabling conditions such as emphysema and COPD. Was it ableist for the FDA to have banned thalidomide?

The NIH-Wide Strategic Plan makes it clear that a paramount goal of NIH efforts is "to support innovative research ultimately aimed at protecting and improving human health." The word health of course encompasses reduced risks and impacts of disability.

While disability is often difficult to "fix," to borrow language of the report, the vast majority of people with disabilities would have preferred their disabilities be prevented, and if not prevented, then at least alleviated. Perhaps there are people who do not wish to have their disabilities reduced. For example, some deaf people may not wish to hear; some who are blind may not wish to see; some with paraplegia may not wish to walk. But this would be the 1%, not the 99%.

Some might argue that the mission statement's remaining phrase "prevent or reduce illness" would encompass disabling conditions but of course that is not true. For example, autism is not an illness, it is a developmental disorder rooted in abnormal early brain development that causes significant functional disability in the vast majority of cases. Due to unknown causes, this serious mental disorder now affects about 3% of U.S. children, portending catastrophic long-term consequences for our polity. While the need to reduce autism rates has never been more urgent, the new mission statement would not-so-subtly remove any mission to reduce autism, either on an individual or population level. Who would pay the price for this erasure of mission? Americans who count on the NIH to spearhead efforts to identify causes, and also treatments to reduce its disabling impacts, which can include failure to achieve basic communication or living skills, aggression, self-injury, elopement, ingestion of inedible objects, property destruction, and of course lifelong dependency.

With this proposal the NIH threatens to jump into a foreign moral universe detached from its core duties and in conflict with its congressional mandates and the urgent needs and desires of American citizens and taxpayers. We oppose it in the strongest terms possible.

# Suggested additions

The mission statement is adequate as is.

# Suggested deletions

The mission statement is adequate as is.

# Response 376

### **Reflects Strategic Plan**

Office of the Director National Institutes of Health Via NIH submission website submission website

Re: Opposition to Revision of NIH Mission Statement, Notice Number: NOT-OD-23-163

To the Director:

It is difficult for us to believe that the National Institute of Health is actually proposing removal of the goal of "reducing disability" from its mission statement. It is distressing to think that NIH leadership would be willing to dispense with core responsibilities to appease the irrational demands of a trendy identitarian ideology.

Nothing is more important to us than the critical goal of reducing the disability of autism. Here in California we have seen a 50-fold surge of autism cases in our developmental disability services system over just 35 years (and these are cases involving significant developmental disability, not high functioning cases), a staggering increase for which we still have no explanation. This rapid increase is causing untold suffering and burden in our families, while posing existential threats to our systems of support.

While our community clamors for answers and help, the NIH appears willing to shut the door on efforts to reduce disability, which would include autism.

The aim of reducing disability is one of the most important roles the NIH plays in the language of countless federal laws, including the Autism CARES Act. The RFI itself states, "NIH works to turn scientific discoveries into better health for all." Is disability not part of "health," or is "health" now defined as merely the ability to breathe and remain alive?

This proposal is so strange that it is almost as if the Department of Defense consulted with a handful peace activists to set forth, "We propose to no longer protect citizens from foreign

aggression." The NIH proposes an immoral action at odds with its essential mission, under the banner of a most superficial moral goodness.

We ask you to soundly reject the proposal.

Thank you, [redacted]

# Suggested additions

We suggest stronger language that more affirmatively emphasizes the NIH's key role in preventing and treating disabilities: "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 to support the urgent goal of reducing both physical and mental disability."

### Suggested deletions

None.

# Response 377

### **Reflects Strategic Plan**

It does not because it does not include any language that demonstrates a commitment or understanding of equity and thus meeting people where they are, or the fact that the fundamental knowledge is tempered by context. Thus, if we seek fundamental knowledge then we need to ensure we do so within the context of our own human influence on the nature and behavior of living systems, thus ensuring that we can seek knowledge but must adapt to the reality of our society.

### Suggested additions

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

-or-

"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 by building structures that are responsive to the unnatural (racism, capitalism, ableism) factors that influence the core nature of the systems we are studying." (This one is not great but it's to give an idea)

### Suggested deletions

No response.

# Response 378

# **Reflects Strategic Plan**

I agree this new mission statement is a great ideal to follow and captures its goals and objectives.

The term "disability" should not be taken out of the revised mission statement as health without disability or diminishing disabilities is clearly part of the goal and should be kept in the statement.

# Suggested deletions

N/A

# Response 379

# **Reflects Strategic Plan**

No response.

# Suggested additions

Request to include "improve well-being" rationale: include for medical advances that not directly prevent or reduce illness but improve overall well-being of someone living with an illness or disability.

### Suggested deletions

No response.

# Response 380

# **Reflects Strategic Plan**

### An improvement—

"Striving to acquire essential insights into the nature and behavior of living systems, and utilizing this understanding to enhance overall health. Our mission is to prevent and reduce illness, promoting well-being and vitality for diverse communities."

### Suggested additions

No response.

# Suggested deletions

No response.

# Response 381

# **Reflects Strategic Plan**

No response.

# Suggested additions

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

I agree that our goal should be lengthening life. Optimizing health and reducing/preventing illness share the common goal of enhancing thr quality of life which may also be achived in other ways, thus the specific addition of "enhancing life."

# Suggested deletions

No response.

# Response 382

### **Reflects Strategic Plan**

The new mission statement strives to clarify the efforts and new found knowledge the NIH are being applied directly to all people, which does indeed coincide with the new objectives. Especially with efforts such as the All of Us program, iCure, and HEAL where that knowledge is not only obtained through diverse efforts, but applied back to the same diverse community.

### Suggested additions

Nothing to note.

### Suggested deletions

Nothing to note.

# Response 383

### **Reflects Strategic Plan**

We have a reduced life expectancy here in the USA compared to other high income countries in the OECD. I am not sure eliminating the "lengthen life" portion of the mission statement is wise. Life expectancy and life length are two measurable and comparable data points to assess whether we are successful in the application of knowledge to reduce or prevent illness.

I do certainly appreciate the addition of the word "all" people.

Unless there will be another government entity looking at "disability," I believe this word should stay.

### Suggested additions

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

NIH can not ignore persons living with disability, and we should work toward preventing disability secondary to illness.

We know from the Global Burden of Disease that Years of Life Lost, Years Lived with Disability and Healthy Life-Years Lost are all key indicators of the quality of health care and health status in a country.

### Suggested deletions

# **Reflects Strategic Plan**

Yes, it does reflect the mission and is less ableist.

### Suggested additions

No response.

### Suggested deletions

Disability.

# Response 385

### **Reflects Strategic Plan**

No response.

### Suggested additions

I believe that the phrase "reduce disability" should be added back into the mission statement. So "...prevent or reduce illness and disability..." is what it should say. Having a disability is not good. If I could get rid of my disabilities, I would. There is no world in which my damaged lungs and other parts of my body are good and to pretend otherwise is to act as though people like me do not exist. Calling me disabled does not imply that I am inherently a bad person. Removing the word "disability" is caving to a miniscule part of the disability community at the expense of the rest of us.

### Suggested deletions

No response.

# Response 386

### **Reflects Strategic Plan**

Yes, I believe that the proposed new mission statement reflects the goals and objectives of the NIH strategic plan.

### Suggested additions

After lengthy consideration, I believe that the proposed language is suitable in this context. The word "health" did give me pause, because it is not defined here—and it raises concerns about the "medical model" of disability. The World Health Organization has a definition of the word "health" which I endorse. However, it is long and may raise some controversial questions that you do not need in this context. You need something brief and to the point. As said in JAMA Viewpoint on this change (doi 10.1001/jama.2023.20123), "the word 'health' also has various definitions." Nevertheless, it is hard to argue against health.

### Suggested deletions

None.

# **Reflects Strategic Plan**

I ABSOLUTELY disagree with the proposed changes!!!! The goal should always be towards reducing BOTH illness and disability, through research, safety practices, maternal health, and any means possible. The notion that "reducing disability" implies ableism is a serious denial that disabilities even exist. Disabilities encompass an extremely broad spectrum, including conditions that are extremely debilitating, costly to families and taxpayers, and limiting to the quality of life of thousands of disabled individuals and their families. Stripping away services and supports that could potentially reduce the number of people who live with disabilities is irresponsible and should not be a part of this mission statement.

# Suggested additions

... lengthen AND IMPROVE QUALITY OF LIFE...

# Suggested deletions

LEAVE IT!

# Response 388

# **Reflects Strategic Plan**

As a parent of a child with Profound Autism, I want to express my full support for [organization redacted]'s position requesting to maintain the focus on "reducing disability" within the NIH's mission statement. This stance resonates deeply with my own experiences and aspirations for my child & countless others like them.

The goal of "reducing disability" is not about devaluing individuals with disabilities; rather, it's about recognizing that each person, regardless of their abilities, has the potential to lead a fulfilling & independent life. For parents like me, it's about fostering opportunities for our children to acquire skills & gain greater independence.

# Suggested additions

In the case of my child, who has Profound Autism, I understand the challenges and the importance of early intervention and support. It's not about diminishing their worth; it's about providing them with the tools and resources they need to navigate the world more effectively. Like countless other parents, I dream of a future where my child can communicate, engage in daily activities, and live with greater autonomy, even though the likelihood of this happening is low. With my daughter's disability and co-occurring disabilities, she is likely to require high support levels for even basic needs communicating, toileting, dressing, bathing, and safety.

# Suggested deletions

Reducing disability is a moral & pragmatic imperative. It's about offering individuals with disabilities the chance to live their lives to the fullest, free from unnecessary limitations. Examples, such as early screening & intervention for autism & addressing its disabling impacts, resonate with my hopes & aspirations for my child.

I believe that maintaining a focus on "reducing disability" within the aligns with the urgent needs and desires of parents, caregivers, & individuals with disabilities themselves. It reflects our collective commitment to improving the lives of autistic children and adults.

Thank you for speaking out and championing the rights and opportunities of all individuals with disabilities.

# Response 389

### **Reflects Strategic Plan**

No response.

### Suggested additions

I do not fully understand why reducing disability was removed from this statement. Quality of life should be an important goal to any mission statement Reducing disability should be a key focus to improving the health and life of others. You had it correct before. Please revise and add it back in.

### Suggested deletions

No response.

# Response 390

# **Reflects Strategic Plan**

As the parent, and potentially lifetime caregiver of a profoundly autistic son (and spouse of a cancer and HIV researcher) I oppose the revision of the mission to remove the reduction of disability in the strongest terms possible.

To quote the [organization redacted], "This argument rests on a clear logical fallacy: it conflates 'disability' with 'individuals who have disabilities." Disability itself is not a neutral state of identity; by its very nature it means impairment, dysfunction, and incapacity. This fact is mutually exclusive from the other fact at hand: individuals with disabilities have value and should not be stigmatized.

It should go without saying that the goal of reducing disability, i.e., impairment, on both a population and individual level is a moral and pragmatic imperative that does not carry any animus toward individual people whose functioning is limited by their disabilities. Our collective desire to eradicate polio hardly demeans those individuals who have fallen victim to polio-caused paralysis. Our aim to reduce fetal alcohol spectrum disorder, and all the disability it can entail, does not mean we believe those affected are morally flawed, or flawed in the sense of any abstract philosophies. Wanting to reduce these and countless other impairments that reduce functioning and human potential—multiple sclerosis, ALS, schizophrenia, the list is long—hardly equates to "ableism."

When an obstetrician unwraps an umbilical cord choking a neonate, and therefore reducing the risk of lifelong impairment, is she engaging in ableism, or rather the most honorable sort of humanity? By any reasonable standard, disability should be prevented whenever possible. Laws mandating helmets and seat belts are not "ableist"; they protect the public from preventable injury and consequent disability and all the costs, burdens, pains and dependencies that result. When a pregnant woman takes folic acid supplements to reduce risk of spina bifida in her child, she is not "ableist," she is obviously taking prudent preventive measures to reduce the risk of serious impairment in her child. Countless public health campaigns and NIH efforts shine a light on the risks of smoking, to reduce the prevalence of disabling conditions such as emphysema and COPD. Was it ableist for the FDA to have banned thalidomide?

While disability is often difficult to "fix," to borrow language of the report, the vast majority of people with disabilities would have preferred their disabilities be prevented, and if not prevented, then at least alleviated. Perhaps there are people who do not wish to have their disabilities reduced. For example, some deaf people may not wish to hear; some who are blind may not wish to see; some with paraplegia may not wish to walk. But this would be the 1%, not the 99%.

Some might argue that the mission statement's remaining phrase "prevent or reduce illness" would encompass disabling conditions but of course that is not true. For example, autism is not an illness, it is a developmental disorder rooted in abnormal early brain development that causes significant functional disability in the vast majority of cases. Due to unknown causes, this serious mental disorder now affects about 3% of U.S. children, portending catastrophic long-term consequences for our polity.

While the need to reduce autism rates has never been more urgent, the new mission statement would not-so-subtly remove any mission to reduce autism, either on an individual or population level. Who would pay the price for this erasure of mission? Americans who count on the NIH to spearhead efforts to identify causes, and also treatments to reduce its disabling impacts, which can include failure to achieve basic communication or living skills, aggression, self-injury, elopement, ingestion of inedible objects, property destruction, and of course lifelong dependency.

The NIH should be at least the one institution in this country that all autistic Americans can look to for research based on the mission of improving quality of life. Profoundly autistic individuals are already talked over and their needs shoved aside by the loudest voices (not the majority) in the community, who tend to be the least impaired on the spectrum. It's the equivalent of someone nearsighted demanding to make all policy for the congenitally blind, because they, "share a diagnosis." Their struggles are vastly different, and while they're both valuable people, one is clearly more disabled than the other. And if research could provide the ability to simply be nearsighted instead of blind, I highly doubt that the blind would find anything ableist in having that choice.

# Suggested additions

How about something along the lines of, "improve quality of life for people with disabilities?" Perhaps you're not implying autistic people wouldn't be autistic, or deaf people wouldn't be deaf, etc. Rather instead you're mission is to provide them the most opportunity for independence and self-advocacy by reducing severity associated with certain disabling conditions.

# Suggested deletions

Honestly, I think what you're being asked to do is ableism, i.e. the whitewashing of disabilities to make them more palatable for a society that loves inspiration porn, and doesn't want to deal with the harsh reality that the most severely cognitively disabled typically end up homeless or imprisoned. A simple text change starts the systemic erasure

of the /acknowledgment of existence/caring for thousands of severely disabled adults in the coming decades.

# Response 391

## **Reflects Strategic Plan**

Removing disability from the mission statement is not acceptable as it then lumps people with disabilities into "reducing Illness." People with disabilities are often not suffering from an illness. Instead you could say "optimize heath and functionality and reduce illness." Many existing measures of disabilities (activities of daily living and instrumental activities of daily living) measure the ability to function independently.

### Suggested additions

"To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to optimize health and functionality, and reduce illness and disability."

Many existing measures of disabilities (activities of daily living and instrumental activities of daily living) measure the ability to function independently. These measures/assessments are used by many systems of care as an eligibility tool to see if someone needs extra help to live in their community. NIH's mission should be to enhance functionality by increasing research into equipment/tech, therapies, medications, surgical interventions, etc. A wheelchair helps some people function, physical therapy helps some people function, cognitive behavioral therapy helps some people function, medication helps some people function—the list goes on.

#### Suggested deletions

No response.

# Response 392

#### **Reflects Strategic Plan**

I run a grassroots group of some 300 families located in [redacted], about half of whom have adult children with ASD.

In no way should the NIH create the impression that autism is just a new normal. While some with an ASD diagnosis are fully functional and productive members of society, and it's nice and correct that NIH welcomes them as equal participants and partners, a large number of individuals with an ASD diagnosis have SEVERE life-limiting disabilities. NIH must continue to work on preventing these severe disabilities.

I'd add that your proposed new definition also suggests NIH is not interested in trying to prevent Fetal Alcohol Syndrome Disorders.

We must continue to work towards preventing disabilities!

#### Suggested additions

No response.

#### Suggested deletions

### **Reflects Strategic Plan**

I'm not sure why the NIH would want to change this specific and important language in its mission statement? It's amazingly important that an institution entrusted in improving everyone's health should clearly advocate for all in need, including people with disabilities. Specific language helps to ensure that many of the people realize that they are being considered when decisions about funding and policy are made. Please consider this.

#### Suggested additions

No response.

#### Suggested deletions

No response.

## Response 394

### **Reflects Strategic Plan**

"Lengthen life" should be part of the mission statement.

That should be a core goal.

#### Suggested additions

"Lengthen life" should be part of the mission statement.

That should be a core goal.

#### Suggested deletions

No response.

### Response 395

#### **Reflects Strategic Plan**

No response.

#### Suggested additions

"To see fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to optimize health and prevent disabling conditions for all people."

"Illness" and "disability" are equal in the eyes of those that suffer. I hope you chose the word "illness" because it is equal to "disability"—that it is redundant to say both. Perhaps using the words, "disabling conditions," instead of "illness," will help to remove the stigma of illnesses such as autism whose cause is yet to be discovered, as are the causes of many diseases. If you are excluding "disabilities" from the NIH statement, I believe this to be a mistake which will harm many people who need you.

#### Suggested deletions

### **Reflects Strategic Plan**

This is a very good and needed change to the mission statement.

#### Suggested additions

I think it is good as it is.

#### Suggested deletions

I think this is good as it is.

## Response 397

#### **Reflects Strategic Plan**

Removing disability from the mission statement is not acceptable as it then lumps people with disabilities into "reducing Illness." People with disabilities are often not suffering from an illness. Instead, you could say "optimize heath and functionality and reduce illness." Many existing measures of disabilities (activities of daily living and instrumental activities of daily living) measure the ability to function independently.

#### Suggested additions

"To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to optimize health and functionality and reduce illness and disability."

#### Suggested deletions

Many existing measures of disabilities (activities of daily living and instrumental activities of daily living) measure the ability to function independently. These measures/assessments are used by many systems of care as an eligibility tool to see if someone needs extra help to live in their community. NIH's mission should be to enhance functionality by increasing research into equipment/tech, therapies, medications, surgical interventions, etc. A wheelchair helps some people function, physical therapy helps some people function, cognitive behavioral therapy and ABA therapy helps some people function, medication helps some people function—the list goes on.

### Response 398

#### **Reflects Strategic Plan**

The proposed new mission statement is much better.

#### Suggested additions

No response.

#### Suggested deletions

### **Reflects Strategic Plan**

I have been a patient at NIH's National Eye Institute for many years. After I was diagnosed with Retinitis Pigmentosa in elementary school, I began visiting the 10th floor for my yearly check ups with my father and sister who also have the disease. RP affects my peripheral and night vision, and will eventually lead to blindness. Since leaving the Baltimore/DC area, I have continued to receive care for my eyes at other prestigious hospitals and research centers. I go every year in hope to do exactly what your current mission states. I hope that by helping the doctors and scientists understand my disease, they can begin to reduce this disability in me and others. Without that, I cannot drive at night, I cannot enjoy the stars in the sky, I cannot move around freely without running into other people. I cannot live a normal life. This, by no means that I am ashamed or embarrassed by my disability. I embrace it. I ask for help. I educate others about low vision and the spectrum on which I find myself. But that does not mean I don't want a cure. I frankly find it offensive that you would downplay the work my doctors at the NEI do to help cure my disability. I do not want to live like this. That is not the same thing as saying that I do not celebrate and appreciate the hand I have been dealt. By muddling the two and removing the work "disabled" from you statement, you remove me. You remove what little explanation I have when I tell people why I ran into them at the store. I'm different and that is ok but that does not mean I do not want to fixed. Keep the mission statement the same and keep helping people with disabilities like me.

### Suggested additions

Nothing. It is fine the way it is.

### Suggested deletions

Nothing. It is fine the way it is.

### Response 400

### **Reflects Strategic Plan**

No response.

#### Suggested additions

NIH's mission is to seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, with continuous research of illnesses and diseases and educate to eliminate the stigma associated with challenging disabilities.

Added the last sentence after the words lengthen life: reason to change how people may view disabilities with a better understanding; people may be unintentionally ignorant, but knowledge with understanding is key.

#### Suggested deletions

## **Reflects Strategic Plan**

I like it. I does reflect the new goals and objectives.

### Suggested additions

None.

#### Suggested deletions

None.

## Response 402

### **Reflects Strategic Plan**

No it does not. "Reducing illness and disability" is a great goal and therefore the current mission statement constitutes appropriate language for the NIH. Please recall that for most people the present goal and mission statement wording to "seek fundamental knowledge" is important primarily due to the urgent need to reduce illness and disability.

#### Suggested additions

If the mission statement changes in any way then I would prefer the changes to emphasize the "reduce illness and disability" goal over the pure science drive to "seek fundamental knowledge." There is urgent need to improve treatment options for people with autism spectrum disorder as well as bipolar, schizophrenia and schizoaffective disorder.

#### Suggested deletions

Proposed mission statement is a word salad that detracts from the institute's primary goals and risks a slide into missed opportunities for needed treatment options which will result in diminished support for the NIH as it becomes less relevant to the populace.

# Response 403

### **Reflects Strategic Plan**

I became aware of this change via a Facebook post for a group, [organization redacted]. It shared the position statement from the [organization redacted], who provided feedback. I agree with their assessment and disagree with your proposal to remove "reduce illness and disability" to appease those that find the language ableist.

I am the sibling of an adult (61 years old) with intellectual / developmental disabilities. My late father SUFFERED from chronic pain due to nerve issues and was considered "disabled" since I was 10 years old. My 92 year old mother has mobility issues and SUFFERS from chronic pain. I'm the caretaker for my boyfriend who SUFFERED a stroke two years ago and is now disabled (left-side hemiparesis); he lives each day wanting to use his arm and walk without a cane—to no longer be disabled. I SUFFERED from debilitating migraines for decades that affected my quality of life. SUFFERED. With the exception of my brother, whose disability puts him at risk of being unsafe and unable to care for himself, we suffer.

Reducing this disability, this SUFFERING, is a worthy mission.

It doesn't mean those with a disability are less than.

It can be interpreted that under the new mission statement, the NIH would continue to prevent stroke, but do little to address those disabled in the wake of a stroke.

To me, the proposed new language that erases "disability" illustrates the danger of being too "woke." It will do harm to those amazing, capable, wonderful individuals that I love who have disabilities who suffer from them.

#### Suggested additions

Don't be scared of the word "disability."

#### Suggested deletions

No response.

### Response 404

### **Reflects Strategic Plan**

I am absolutely disgusted that the NIH would have gotten to the stage where it even contemplates excluding the alleviation of disability from its mission statement.

Disability is not a one-off. Most people by the time of adulthood experience some form of disability somewhere along its continuum, whether it's minor vision impairment (needing glasses) or hearing loss or minimization of mobility (sore knee/foot) to the more extreme forms such as blindness and para/quadri/ plegia or mental illness. And in virtually all cases where such disability impairs one's enjoyment of life or ability to pursue one's goals, there is a desire to alleviate the disability. No one "embraces" disability; one puts up with it as best one can, and, if offered the chance to alleviate it, most certainly takes it.

To imply there is something wrong with alleviating disability, to embrace "ableism," is to deny the reality of misery as a heavy weight upon an individual, and implies there is something wrong with wanting to be free of disability, and that there is something wrong with asking for society's help in overcoming disability.

Yes, I am aware some people who are disabled in some way do not see it as such, and have even found meaning in their disability. Rick Hansen is one such individual. But not every disabled person has the will or means to rise above his or her disability. All that "ableism" does is condemn that vast majority to lives of trial and misery and shame for even wanting to be whole again.

It is the role, if there exists any role at all, of the medical community to alleviate healthrelated suffering where such is possible. It is redundant to add "where such is desired." No one wants to suffer, and no one who is suffering wants to be told to suck it up and embrace your suffering because it is somehow more noble to suffer in silence than to seek out a remedy.

It is no surprise that "ableism" is finding favor in some quarters today. In our Great Reset New World Order, we will own nothing, eat bugs, live in pods and be happy. And shut up about our problems, including our disabilities.

### Suggested additions

If anything, reinforce the current language regarding the alleviation of disability.

### Suggested deletions

No response.

# Response 405

## **Reflects Strategic Plan**

It's certainly an improvement, but a keyword search on the strategic plan (disab#) reflects only the prior ableist language about disability reduction. It would be nice to see this modified also, and I expect a lot more from the 2025–2029 plan.

As a 60-year scientist who studies disability, and simultaneously manages my own disability, I've felt profoundly marginalized by the NIH and its program administrators. I've been a PI on about \$4m worth of government-sponsored disability research, with nearly all of it coming from the National Institute on Disability, Independent Living and Rehabilitation Research. I've submitted five grant applications to the NIH and received zero dollars. In most cases, I wasn't even scored. This does not count the times I reached out to FOA competition managers and was told that my ideas for disability research would not be deemed responsive without a very narrow and explicit focus on a single diagnostic group.

I really hope the NIH moves with alacrity to change its mission statement and makes all the other changes recommended by the disability subgroup to the Working Group on Diversity and unanimously endorsed by the Advisory Committee to the Director of NIH.

### Suggested additions

No response.

### Suggested deletions

No response.

# Response 406

### **Reflects Strategic Plan**

No response.

### Suggested additions

To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to optimize health, lengthen life, and prevent or reduce illness.

### Suggested deletions

Can include "all people" or exclude "all people." Either way is fine. Perhaps, include "lengthen life" as mentioned in the old mission statement.

## **Reflects Strategic Plan**

Overall, [organization redacted] finds that the proposed revisions to the National Institutes of Health (NIH) mission statement remain aligned with the three core objectives and five cross-cutting themes of the current NIH-Wide Strategic Plan. [Organization redacted] also appreciates the responsiveness of the proposed changes to the recommendations received from the thought-leaders serving on the Advisory Committee to the Director Working Group on Diversity, Subgroup on Individuals with Disabilities. In our responses to Questions 2 and 3, we highlight additional edits to further align the revised mission statement to the NIH-Wide Strategic Plan and further refine language that could be perceived as ableist.

[Organization redacted] recommends the following revised statement: To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to protect and improve health and alleviate illness for all people.

### Suggested additions

As indicated in our response to Question 1, [organization redacted] 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. Our concern with "optimize" is that it is a term used to describe objects or actions (e.g., treatments, interventions, and cures, as highlighted within Objective 1 of the NIH-Wide Strategic Plan) rather than people. The suggested replacement—"protect and improve"—also appears in the opening paragraph of the NIH-Wide Strategic Plan. Similarly, the phrasing "prevent or reduce" still closely resembles the language of the original mission statement. Therefore, we recommend replacing with "alleviate" to address concerns that the proposed revisions could be interpreted as perpetuating ableist beliefs.

(Note: Since we are recommending revisions, responses to Questions 2 and 3 are the same.)

### Suggested deletions

As indicated in our response to Question 1, [organization redacted] 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. Our concern with "optimize" is that it is a term used to describe objects or actions (e.g., treatments, interventions, and cures, as highlighted within Objective 1 of the NIH-Wide Strategic Plan) rather than people. The suggested replacement—"protect and improve"—also appears in the opening paragraph of the NIH-Wide Strategic Plan. Similarly, the phrasing "prevent or reduce" still closely resembles the language of the original mission statement. Therefore, we recommend replacing with "alleviate" to address concerns that the proposed revisions could be interpreted as perpetuating ableist beliefs.

(Note: Since we are recommending revisions, responses to Questions 2 and 3 are the same.)

### **Reflects Strategic Plan**

NIH must recognize and support the need for scientists to become effective communicators of their work and their roles in society. Before scientists participate in science outreach activities (e.g., teaching, science cafes, museums, school demos, engaging w policymakers) they should receive formal training in speaking, reducing complex data, advanced listening skills, connecting with the audience, and storytelling. Published surveys indicate researchers at all levels of science careers want to get SciComm training. Requiring recipients of all NIH grants (especially T, F, K, R25 grants) to receive formal communication training would be useful. (This requirement would parallel to need for guidance on responsible conduct of research.) Providing modest supplements to NIH awards to support SciComm training (and trainers) might be necessary, but not overly costly.

### Suggested additions

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

Science funded by NIH must be communicated to the general public, other scientists, news agencies, STEM students at all levels, policymakers, underserved/minority communities, funding agencies/philanthropists, family and friends. "Applying the knowledge" implies only a limited range of communities will benefit from NIH-supported research. NIH-supported knowledge must be shared in simple, understandable, and impactful ways to everyone. Thank you.

### Suggested deletions

No response.

### Response 409

#### **Reflects Strategic Plan**

The new mission statement reflects the Plan.

For my own work I'm glad that the first part of the mission statement, "To seek fundamental knowledge about the nature and behavior of living systems," is unchanged since that is what I do.

The change "and the application of" to "to apply" is a good change because it avoids the passive.

I'm ok with the change about disability if that's how people feel.

### Suggested additions

"to enhance health, lengthen life, and reduce illness and disability." to "to optimize health and prevent or reduce illness for all people."

I'm wondering why NIH would no longer be interested in lengthening life for those who want it? So a possible revision would bring that back in:

"to optimize health, lengthen life, and prevent or reduce illness for all people."

### Suggested deletions

None.

# Response 410

## **Reflects Strategic Plan**

Just wanted to put in my feedback that I really like and support the change. Sometimes making changes to wording can appear as almost a trivial thing, but I think this change in wording is going to have great positive repercussions. Often improving accessibility for a marginalized community ends up improving things for all (see curb cut effect).

I'm someone that has disabilities that (luckily?) am able to mask and do not self report. That does not mean that the challenges aren't real and privately I do identify as someone with disability. A large part of my refusal to self declare is that I want to be a person first. I want any conversations to be about how my needs can be met, not about how I need to be fixed. I love your language change. It makes it clear that the focus is on the right things with still improving lives (yay! I love the NIH), but not at the cost of losing my identity as a human person.

You might like the writings of Nicola Griffith, who I feel has been leading this conversation for a long time. I'm not her (I promise), just a huge fan. I would love to see some interaction or interview between her and relevant folks with the NIH that can discuss the impact of this change. Words are hard, and finding an articulate writer can be so powerful. https://nicolagriffith.com/2021/08/20/my-ms-resume/

### Suggested additions

It's great, no suggestions.

### Suggested deletions

It's great, no suggestions.

# Response 411

### **Reflects Strategic Plan**

To whom it may concern:

On behalf of the members of the [organizations redacted], we are pleased to respond to a request from the National Institutes of Health (NIH) for public comments on the agency's revised mission statement.

NIH is the primary source of competitive, discretionary grant funding supporting the population sciences. As a result, [organizations redacted] monitor and often respond to proposed changes governing NIH extramural policy and research activities.

The NIH mission statement is used to inform and guide the NIH Institutes and Centers' (ICs) governing policies and operations. As stakeholder organizations, [organizations redacted] reference the NIH mission statement in communications with scientists, policymakers, and the general public. The current statement helps reinforce how NIH recognizes the behavioral and social sciences as part of the agency's overarching mission.

That being said, we do not believe the revised mission statement undermines NIH support for behavioral and social science research (BSR). In fact, we believe the term "optimize health" clarifies and reinforces NIH commitment to supporting research regarding the impact of developmental, life course events on outcomes, including functioning and longevity. Despite our understanding, [organizations redacted] urge NIH to clarify its understanding of the language's intent and to reassure the community that the proposed statement does not signal diminished NIH support for BSR.

Thank you for considering our views as you finalize the revised NIH mission statement. Please do not hesitate to contact us if our organizations can be of further assistance.

### Suggested additions

No response.

## Suggested deletions

No response.

## Response 412

### **Reflects Strategic Plan**

The proposed new mission statement for the NIH more accurately reflects goals and objectives of the NIH-wide strategic plan. The old mission statement's use of the phrase "reduce disability" could be interpreted to promote eugenics, a philosophy which is antithetical to two of the strategic plan's stated objectives: "assuring ethical and equitable conduct of research through inclusion" and "improving minority health and reducing health disparities."

### Suggested additions

We are people with disabilities advancing justice, access, and inclusion for the Disability Community. Our vision is a fully accessible community where disability is valued as human diversity and everyone belongs.

While we applaud the proposal to remove the phrase "reduce disability" from the NIH mission statement, we believe that disability should not be erased entirely from the mission of NIH. Disability is a natural part of human diversity that should be accepted and accommodated. Therefore, we suggest the following mission statement: "To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to improve health, increase quality of life, and prevent or reduce illness for all people, regardless of ability."

We suggest using the word "improve" rather than "optimize" because plain language is more cognitively accessible. We suggest including the phrase "increase quality of life" because this allows the NIH to fund research into disability support services that may significantly improve quality of life for people with disabilities without directly improving health. Including the phrase "regardless of ability" highlights the NIH's commitment to inclusion of people with disabilities in its work.

### Suggested deletions

We recommend replacing the word "optimize" in the proposed mission statement because reasonable people may disagree on what "optimal" health means to them, and it can be interpreted to imply that there is a "perfect" or "ideal" way for human bodies to exist. The concept of the "ideal" human being has historically been used to harm many marginalized groups, including the Disability Community. We suggest using the phrase "improve health" instead of "optimize health."

# Response 413

# **Reflects Strategic Plan**

No response.

## Suggested additions

My role is both as an Administrator and an Advocate. Below are drafts of two options I'm proposing for new language:

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

or

"To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to optimize health, prolong life, create opportunities for better health outcomes for all."

Both of these suggestions are borne out of a drive to highlight that those with disabilities should not be excluded from inclusion in studies not focused directly on their disability, AND the need to communicate that everyone with disabilities has a personal choice over what "healthy" looks like to them (disabled isn't a bad thing).

### Suggested deletions

See above.

# Response 414

### **Reflects Strategic Plan**

The NIH-wide strategic plan currently in place outlines three broad objectives: advancing research; building and maintaining research capacity; and exemplifying the highest level of scientific integrity and public accountability in the conduct of science. All three of these objectives align with the proposed revised mission statement.

Seeking fundamental knowledge about the nature and behavior of living things, and applying that knowledge to optimize health, requires support for research across the continuum from basic to translational to clinical. By undertaking a broad portfolio of research across disciplines and supporting the training of the next generation of scientists, NIH invests in generating the fundamental knowledge that is necessary to advance biomedical science and ultimately improve the health of all people. For the results of research to be effectively applied to optimize health and prevent or reduce illness in all people, those results must be generated with rigor and reliably reported. The third objective in the current strategic plan addresses this need by calling for the highest level of scientific integrity, public accountability, and social responsibility in the conduct of science.

As a global and multi-disciplinary community of scientists, many of whom are supported throughout their careers by the NIH, [organization redacted] supports the language in the proposed revised mission statement and appreciates the opportunity to provide input.

## Suggested additions

[Organization redacted] recommends that NIH consider including the phrase "improve the quality of life" after "optimize health" in the proposed mission statement. An important aspect of medicine is to alleviate suffering due to illness or disease. Modern medicine has developed many treatments that turned previously lethal health threats into chronic conditions that are managed over the long term. This addition would expand the NIH mission to include research into ways to help individuals with health challenges live healthier lives.

## Suggested deletions

The NIH Advisory Committee to the Director's Working Group on Diversity, Subgroup on Individuals with Disabilities made several actionable recommendations in its December 2022 report, and [organization redacted] is encouraged to see NIH moving forward with implementation. Revision of the NIH mission statement to remove language calling for reducing disability is an important and visible step toward addressing the systemic barriers that exist for persons with disabilities. [Organization redacted] acknowledges that NIH has also recently taken steps to implement additional recommendations from the same report by formally designating people living with disabilities as a health disparity population and issuing a funding opportunity for research on health and health care disparities among persons living with disabilities. [Organization redacted] urges NIH to continue to pursue implementation of the report's recommendations, including those aimed at eliminating barriers to full participation in the scientific workforce for persons with disabilities.

# Response 415

# **Reflects Strategic Plan**

"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."

The process of prioritizing and evaluating impact of goals need to change.

### Suggested additions

To establish standards for impact on health interventions and outcomes that enable exceptional science and foundational ideas to get recognized and promoted within the established NIH work-force.

### Suggested deletions

### **Reflects Strategic Plan**

No, the proposed new mission statement excludes 2 very important societal goals for US taxpayer funded biomedical research: NIH must remain charged with the goal of lengthening lifespan, and preventing and mitigating physical disabilities. Lifespan measurement has decreased dramatically in just the last 3 years, and millions of people already are, and many more will become, disabled by Long Covid. No commercial entity has the financial motivation to pursue these objectives, only the NIH can prioritize, fund and direct the research and development of solutions to these goals.

### Suggested additions

Maintain the current mission statement as it currently exists.

#### Suggested deletions

Do not alter the current mission statement.

# Response 417

#### **Reflects Strategic Plan**

No response.

#### Suggested additions

Consider adding "well-being" after the word "health" to include all the QOL outcomes that are so important to patients.

#### Suggested deletions

No response.

### Response 418

### **Reflects Strategic Plan**

Either/both the NIH- strategy and/or the language of the mission statement should reflect what's meant by funding the "best" science.

#### Suggested additions

The "Best" science is a value proposition.

A return on investment. When 400000\$ of federal funds are used to provide proof of concept for 13 billion\$/year return, that is an incredible return on investment, and a proposition that should be supported.

An individual whose science was denigrated is closed peer reviewed committee meetings and scientific assemblies, and who them had to personally file for patent protection to "prove" to federal agencies that the science was worthy of advancement should be supported, and not buried by the system of governance.

### Suggested deletions

No response.

# Response 419

## **Reflects Strategic Plan**

Thank you for the opportunity to provide feedback on the proposed changes to the NIH mission statement. Please accept these comments on behalf of the [organization redacted].

[Organization redacted] applauds the establishment of the NIH Advisory Committee to the Directory (ACD) Working Group on Diversity, Subgroup on Individuals with Disabilities and commends the careful thought and consideration that went into these proposed changes and consideration of diverse populations.

[Organization redacted] strongly supports the recommendation to amend the NIH mission statement to better support disability inclusion and remove any perpetuation "of ableist beliefs that disabled people are flawed and need to be fixed". We recognize that the current language has the potential to, unintentionally, further marginalize persons with disabilities. Accordingly, we support the proposed language—"to optimize health and prevent or reduce illness."

## Suggested additions

[Organization redacted] has reservations about the addition "for all people." While we appreciate the intention to be inclusive, our members are concerned that the language may inadvertently obscure the importance of addressing health disparities, a crosscutting theme of the strategic plan. [Organization redacted] encourages NIH to consider slight modifications to the recommendation, for example "...to equitably optimize health and prevent...." or "...to optimize health and prevent or reduce illness equitably across all populations." [Organization redacted] researchers have taught me that it is possible to improve overall health outcomes while overlooking or even exacerbating health disparities.

# Suggested deletions

[Organization redacted] has reservations about the addition "for all people." While we appreciate the intention to be inclusive, our members are concerned that the language may inadvertently obscure the importance of addressing health disparities, a crosscutting theme of the strategic plan. [Organization redacted] encourages NIH to consider slight modifications to the recommendation, for example "...to equitably optimize health and prevent...." or "...to optimize health and prevent or reduce illness equitably across all populations." [Organization redacted] researchers have taught me that it is possible to improve overall health outcomes while overlooking or even exacerbating health disparities.

Thank you again for the opportunity to comment on the proposed changes and offer to be a resource in the future if the need arises.

### **Reflects Strategic Plan**

The newly proposed mission statement reflects some of the goals and objectives as outlined in the NIH-Wide Strategic Plan for Fiscal Years 2021–2025 and is slightly missing a few additional important considerations.

• 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."

### Suggested additions

#### Proposed mission statement:

To seek a fundamental knowledge and collective understanding about the evolving biology and behavior of underlying human health across the lifespan and to apply that knowledge to cultivate healthier outcomes by reducing illness and disability for all people to accelerate progress.

Based on a review of the NIH-Wide Strategic Plan for Fiscal Years 2021–2025 and extensive review of several sections shown below, they proposed revised mission statement is included.

- Understanding Biological, Behavioral, and Social Determinants of Population Health
- Meeting Emerging Public Health Needs
- Partnering to Advance Treatments and Cures
- Enhancing the Biomedical and Behavioral Research Workforce
- Addressing Public Health Challenges Across the Lifespan
- Promoting Collaborative Science

### Suggested deletions

Specific language that could be removed from the proposed mission statement includes "living systems" because the term "living" maybe interpreted as "human beings" and the term "systems" maybe interpreted as "environments or settings" (such as work, housing). The goal is ensure a clearer understanding among all sectors, audiences and decision-makers (including those without a scientific, medical or healthcare education) to increase support.

# Response 421

### **Reflects Strategic Plan**

The new mission statement is much improved.

## Suggested additions

None.

## Suggested deletions

None. It is perfect.

# Response 422

## **Reflects Strategic Plan**

Yes.

## Suggested additions

Consider: "to optimize" could be difficult to understand and may actually mean various things. Would "to improve the health" work? Love "all people." Sometimes "optimization" may not be economically or otherwise feasible; however, "improve" is good. Even small improvements in health are welcome.

### Suggested deletions

Love plain language in science!

Is "fundamental" necessary? Wouldn't all knowledge be welcome?

Also, how about the direct verb: "to learn" instead of "to seek knowledge" and "learning" instead of "knowledge"?

# Response 423

### **Reflects Strategic Plan**

As a special educator, I have seen the term "disability" be used in positive and negative ways. There are groups who embrace the term and see it as part of their identity. Others want to be seen for their strengths and abilities. I believe the proposed mission aligns with the goals and objectives.

### Suggested additions

I have observed individuals with more significant and complex disabilities being treated as objects, not people. They often seem invisible, with limited access to locations and services, in their local communities. I do not want research on disabilities to be excluded, which is the problem with the proposed statement.

However, the current statement with the wording reduce disability could be interpreted as negative.

### Suggested deletions

I am okay with the mission statement as long as the goals and objectives include marginalized groups as part of all people. Words are a first step, but actions have more impact.

### **Reflects Strategic Plan**

I am supportive of the proposed revised mission statement reflecting the goals and objectives as outlined in the NIH-Wide Strategic Plan for Fiscal Years 2021–2025.

### Suggested additions

No suggestions for additional changes. I support ableism.

### Suggested deletions

Removing disability reflects ableism.

# Response 425

### **Reflects Strategic Plan**

The proposed new mission statement's components reflect the goals and objectives of the NIH Strategic Plan, yet the sequencing of the words proposed may create opportunities to minimize the health of all people and place a focus on illness prevention.

#### Suggested additions

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

Changing the sequencing of the words aligns with NIH Strategic Plan to focus on HEALTH FOR ALL PEOPLE.

### Suggested deletions

N/A

### Response 426

### **Reflects Strategic Plan**

[Organization redacted] strongly supports the update to the National Institutes of Health's (NIH) mission statement as both necessary to clarify the nature of disability-related efforts within the NIH and a more accurate statement of the NIH's work regarding health and disability. [Organization redacted] finds that the proposed revisions to the NIH mission statement align with the NIH-Wide Strategic Plan for Fiscal Years 2021–2025's core objectives and cross-cutting themes.

NIH's current mission statement contains language about "reduc[ing]...disability" that may run afoul of modern conceptions of disability. While there are a number of diverse models to define and address disability, many share a view that disability is "not something that needs to be cured, changed, conquered, or 'normalized." Instead, many see disability as merely one component of a person's multifaceted human experience. Additionally, many individuals with disabilities have called for embracing the actual word "disability" to proudly claim this as an integral part of their identity. By reframing the NIH's guiding mission as one around "optimiz[ing] health" and "reduc[ing] illness," the agency more accurately captures its overall goal to improve the overall health of Americans while embracing the dignity and pride of all Americans with disabilities. The revised mission statement also recognizes that language is not static and evolves.

To that end, [organization redacted] recommends the following revised mission statement: "To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to optimize health, improve quality of life, and prevent or reduce illness for all people."

## Suggested additions

[Organization redacted] recommends the following revised mission statement: "To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to optimize health, improve quality of life, and prevent or reduce illness for all people."

[Organization redacted] recommends that the mission statement include language that addresses health on the continuum that it occurs and includes "improve quality of life." NIH's mission statement needs to take a broader lens, incorporating a public health perspective involving the individual and environment. Including "improves quality of life" recognizes that people, including those with disabilities, are diverse and have unique individual characteristics that are also characterized by the individual's interaction with the physical, psychological, socioeconomic, and political environment.

### Suggested deletions

No response.

## Response 427

### **Reflects Strategic Plan**

I agree with the newly revised mission statement.

#### Suggested additions

No suggestions.

### Suggested deletions

Nothing needs to be removed.

### Response 428

### **Reflects Strategic Plan**

While I do not think the prior inclusion of disability was stigmatizing; however, I think the new mission statement is superior.

#### Suggested additions

No response.

#### Suggested deletions

The new statement implies that people are all that we care about. Is that the case? "for all people."

I wouldn't be surprised if some people begin to identify as "not people" in the near future, so we could preclude that future potential challenge.

# Response 429

### **Reflects Strategic Plan**

The faculty of the [organization redacted] support the proposed update to the National Institutes of Health mission statement. Below, we summarize the support expressed by faculty across our campus.

The proposed revision to the NIH mission statement is a strategic and forward-thinking refinement that aligns with contemporary perspectives on health and inclusivity. By shifting the focus from specific outcomes such as "lengthening life" and "reducing disability" to a more comprehensive goal of "optimizing health," the NIH embraces an all-inclusive approach to well-being.

The inclusion of the phrase "for all people" reflects a commitment to inclusivity and acknowledges the diverse health needs of individuals across various backgrounds and experiences. This change reinforces the NIH's dedication to addressing the conditions and concerns that matter most to communities, emphasizing a mission that is not only scientifically rigorous but also socially responsible.

Furthermore, the revised statement aligns with evolving paradigms in health advocacy, respecting the autonomy and positive identity of individuals with varying abilities. The removal of "reducing disability" recognizes the multifaceted nature of disability and supports the view that disability is a positive or neutral aspect of identity, rather than a condition to be reduced.

These proposed changes affirm the NIH's commitment to seeking fundamental knowledge about living systems and applying that knowledge in a manner that goes beyond the mere absence of illness. The term "optimize health" captures the principle of promoting overall well-being, acknowledging the varied and unique health states that individuals may experience. This updated mission statement reflects the NIH's dedication to the highest standards of research, inclusivity, and a mission that resonates with the values of diverse communities we aim to serve.

#### Suggested additions

No response.

### Suggested deletions

No response.

# Response 430

### **Reflects Strategic Plan**

The following feedback and suggestions are provided on behalf of the [organization redacted]. As an organization, we are commented to supporting public policies that address disparities in health care and ensuring clear and concise communications regarding all aspects of health care, including research and outcomes.

The proposed revisions to the mission statement support the following three primary objectives:

1. Advancing biomedical and behavioral science

2. Developing, Maintaining, and Renewing Scientific Research Capacity

3. Exemplifying and promoting the highest level of scientific integrity, public accountability, and social responsibility in the conduct of science

However, two important aspects to support objectives and cross-cutting themes were not reflected in the proposed changes: (1) reducing health care disparities and (2) the importance of communication.

Health care inequities exist across the continuum of health care from systemic barriers to lack of inclusion in research efforts. Disparities have an impact in all aspects of the work of NIH. However, efforts to reduce health care disparities are not addressed in the proposed mission statement. It is unclear if using the term "for all people" is intended to reflect inclusivity. If that is the intent, [organization redacted] suggests reinforcing equitable as opposed to equal services. Please consider modifying the wording to reinforce the importance of promoting health equity and health care equity for diverse populations.

In addition, public health efforts, including access to research that supports optimization of health outcomes, hinges upon the ability to communicate that research effectively and clearly. Elements of communication are interwoven throughout the strategic plan and objectives. It is critical to punctuate the importance of communication by including it in the mission statement.

To address these two important aspects, [organization redacted] recommends the following modifications to the mission statement so that it reads:

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

# Suggested additions

As mentioned above, the final wording of the proposed mission statement omits two important aspects—reducing health and health care disparities and communicating knowledge and information to the public. To address these two important aspects, [organization redacted] recommends the following modifications to the mission statement so that it reads:

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

[Organization redacted] suggests adding the words "communicate and" to the mission statement.

Rationale: Objective 3 of the NIH-Wide Strategic Plan outlines the importance of communicating research results. Communication is not only integral to public accountability, but it is also critical to ensure that everyone has a fair and just opportunity to attain their optimal health and to access necessary care. Scientific research can only help the public make informed health care decisions if it is presented in an accessible, clear, and easy to digest manner. [Organization redacted] believes that the addition of "to communicate"

highlights NIH's commitment to become a trusted resource for findable, accessible, accurate, and timely biomedical information.

[Organization redacted] adding the word "equitably" so that it reads "to equitably optimize health and prevent or reduce illness."

Rationale: [Organization redacted] believes that adding the word "equitably" underscores the importance of adapting and responding to public health needs of specific population groups as well as to the diverse needs of certain diagnoses and disorders to advance health equity.

## Suggested deletions

[Organization redacted] suggest removing "for all people."

Rationale: Using the term "all people" may imply that all people should be treated equally with a one-size-fits-all approach to health care, which should not be the intent. [Organization redacted] believes that adding the word "equitably" underscores the importance of adapting and responding to public health needs of specific population groups as well as to the diverse needs of certain diagnoses and disorders to advance health equity.

# Response 431

### **Reflects Strategic Plan**

No response.

### Suggested additions

We represent [organization redacted]. As many of our U.S.-based members, as well as our society, receive funding through the NIH, we welcome the opportunity to provide feedback on the proposed update to the NIH mission statement.

We commend the NIH's decision to remove ableist language from the mission statement. However, we are concerned that the vague terminology in the proposed revision does not reflect the full potential of NIH-funded research to address the needs of people with disabilities.

The meaning of "optimize health" is unclear. "Improve or maintain health" is more specific, and acknowledges that not all healthcare interventions are curative and maintenance may be an appropriate goal in some situations. For this same reason, we suggest rewording "reduce illness" as "reduce or optimally manage illness." (Optimize Health is also the name of a remote healthcare company, which might be seen to benefit from free advertising in the NIH mission statement.)

In addition, there are many ways to define "health," and we have been unable to find an official NIH definition, leaving room for confusion and narrow interpretations of the term, such as "the absence of disease or infirmity." As described in the report prepared by the Advisory Committee to the Director Working Group on Diversity, Subgroup on Individuals with Disabilities, there are two primary models of disability: the medical model and the social model. The proposed revisions to the mission statement still seem to conform to the traditional medical model, with a focus on interventions targeting disease or infirmity ("prevent and reduce illness"). By contrast, the social model of disability focuses on environmental, social, and other barriers to optimal functioning, participation, and quality of

life. These are crucial healthcare outcomes for all patients, including those with disabilities. It is unclear whether interventions addressing such barriers, such as assistive technologies or training for medical professionals, would qualify as methods to "optimize health" for people with disabilities. As such, we suggest specifically including functioning, participation, and quality of life in the mission statement.

To reflect the potential of NIH-funded research to improve all aspects of health for people both with and without disabilities, we propose the following wording for the mission statement:

"To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to improve or maintain health, functioning, participation, and quality of life and prevent, reduce, or optimally manage illness for all people."

### Suggested deletions

No response.

## Response 432

### **Reflects Strategic Plan**

NIH is the world's premier health agency that can advance science to improve the health and wellbeing of people living with ALS. We believe that Dr. Bertagnolli has the experience and drive to focus NIH research efforts on not only finding new treatments for ALS, but also on optimizing the delivery of ALS care so that every person with ALS has the best length and quality of life possible for them.

We believe there is an opportunity for NIH to recast its mission statement and change its culture from funding a research portfolio without consideration of when investments might bear fruit to a more balanced approach. NIH should more explicitly value improving the health of people living today, in addition to valuing fundamental science that can lead to transformative discoveries in the decades ahead. In other words, it is time for NIH to define itself as a health agency that uses science to advance human health, rather than a science agency that studies health.

This challenge would require focusing not only on long-term investments in finding cures but also on solving current challenges of delivering high quality and life-extending care to people with complex conditions like ALS. The NIH mission statement should also reflect the need for research diversity and opportunities for people with disabilities.

Such a mission statement would capture the entirety and overall focus of the main themes of the NIH Strategic Plan to "use the power of science to create a healthier and more productive life for all," as Dr. Francis Collins called for in his director's message. Therefore, we propose a new mission statement for NIH to consider:

"To continuously improve the health of all people and enhance their quality of life through the acquisition and application of scientific knowledge."

We feel health agencies should have mission statements that focus on improving health, and that this version is the best representation of NIH's core mission. It would be an inspiration to the NIH workforce, patient advocacy groups, the research community, and society at large.

### Suggested additions

Please see the above response and suggested language for a new mission statement.

#### Suggested deletions

Please see the above response and suggested language for a new mission statement.

# Response 433

#### **Reflects Strategic Plan**

No response.

#### Suggested additions

[Organization redacted] supports the use or more direct language with the word "apply" but has concerns on the implications and potential meaning and interpretation of "optimize health." [Organization redacted] encourages NIH to explore the use of other wording like "enhance health" or "better health" that have less concerning potential interpretations.

#### Suggested deletions

No response.

## Response 434

#### **Reflects Strategic Plan**

No response.

### Suggested additions

Instead of people use the word all populations.

#### Suggested deletions

No response.

### Response 435

### **Reflects Strategic Plan**

I don't know.

#### Suggested additions

Here's a proposed statement.

To seek fundamental knowledge about the nature and behavior of living systems and apply that knowledge towards optimizing health for all people.

#### Suggested deletions

The strange use of and/or in "and prevent or reduce" seems like it was written by a lobbyist or legal scholar, not a normal person.

Furthermore, illness prevention is a subset of health optimization, so it's redundant.

I also found there were too many uses of the word "to."

# Response 436

# **Reflects Strategic Plan**

Yes.

## Suggested additions

Disabled and chronically ill people should not be excluded from the statement as they are a huge part of the population; especially the aging population. It would be better to acknowledge their stories and offer support to improve their quality of life. The mission statement could be "To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to optimize health, prevent illness, and support people with disabilities and chronic illnesses."

## Suggested deletions

I think the "optimize health" part covers reducing illnesses and offering support is a part of reducing illness.

# Response 437

## **Reflects Strategic Plan**

No response.

### Suggested additions

In the 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," I suggest substituting "persons" for "people." Due to unique nature of the diseases and conditions studied at NIH, "persons" reflects the individual focus on solving these health problems in each person. It represents the level of rigor and scrutiny on a specific patient and their specific problem whether or not they are part of a larger population affected by that problem.

### Suggested deletions

No response.

### Response 438

### **Reflects Strategic Plan**

I don't have the answer to this question, but what is the purpose of including "all people" in this statement? In the current context, it feels like an obvious change in order to course correct for previously ableist language. Would folks who read this statement in the future, not having the current context, understand the need for "all people" in the statement? Why so explicitly mention "all people" in the mission statement? Are the beneficiaries from the NIH all of humanity, Americans, the U.S. population, or none of the above?

### Suggested additions

"to improve patient and human health outcomes"

In my opinion, a substitution of this statement (or something similar) for "to optimize health and prevent or reduce illness in" would make the NIH mission more positive, capture the need for both bed- & benchside science in advancing human health, and avoids explicitly stating the recipients or beneficiaries of NIH research.

## Suggested deletions

"to optimize health and prevent or reduce illness for all people"

What does "optimize health" mean? It reads to me as a very technical and specific yet vague term rather than something publicly-accessible, broad, and aspirational to guide future research endeavors. The phrase "prevent or reduce illness" evokes a similar feeling. Additionally, this phrase "prevent or reduce illness" in particular reads as "our mission is to stop bad things from happening" when, in my opinion, the mission statement should read "our mission is to enable good things to happen."

# Response 439

## **Reflects Strategic Plan**

Indeed, the proposed new mission statement reflects the goals and objective, but a more positive statement would infuse new life into the great world of research.

### Suggested additions

To seek "in-depth knowledge," "through research," about the nature and behavior of living systems and "implementing that gained" knowledge to prevent or reduce illness "thereby" optimising health and wellness of all people.

Till this date, every research work has been carried out on the basis of "fundamental knowledge" that has been passed down through generations and gained over the course of further research.

During the course of the COVID pandemic, the newly gained "in-depth knowledge," "through research," of the virus mechanism helped speed up the process of discovery of vaccine by "implementing that gained" knowledge, which helped prevent or reduce illness "thereby" optimized health and wellness of all people, which in turn saved tens of millions of lives throughout the globe.

### Suggested deletions

To seek "in-depth knowledge," "through research," about the nature and behavior of living systems and "implementing that gained" knowledge to prevent or reduce illness "thereby" optimising health and wellness of all people.

Till this date, every research work has been carried out on the basis of "fundamental knowledge" that has been passed down through generations and gained over the course of further research.

During the course of the COVID pandemic, the newly gained "in-depth knowledge," "through research," of the virus mechanism helped speed up the process of discovery of vaccine by "implementing that gained" knowledge, which helped prevent or reduce illness "thereby" optimized health and wellness of all people, which in turn saved tens of millions of lives throughout the globe.

### **Reflects Strategic Plan**

The [organization redacted] greatly appreciate the opportunity to provide comments on the proposed update to the National Institutes of Health (NIH) mission statement.

The NIH-Wide Strategic Plan has laid out three main objectives to support the mission of the NIH. The proposed new mission statement should not only reflect the strategic plan but also the stakeholders it serves. The mission should not only seek to optimize health and reduce illness but also aspire to enhance function. Enhancing health and optimizing function are not mutually inclusive. The International Classification of Functioning, Disability and Health (ICF) is the World Health Organization (WHO) framework for measuring health and functioning at the individual and population level. Although many individuals may have the same health condition, their response to that condition can vary widely, impacting function in one but not in another.

By neglecting the function aspect, it is neglecting more than 83 million Americans (25%) who are living with some type of disability in the U.S. Those with disabilities are more likely to have difficulty with mobility, cognition, self-care, and living independently, but have a more difficult time with meeting with a health-care provider. The NIH has invested substantial resources into addressing the extent of disability in the US and its widespread public health impact that required a response to improve function, activity, and participation with those individuals with disabilities. In 2016 and updated in 2021, the National Center for Medical Rehabilitation Research laid six objectives in the NIH Research Plan on Rehabilitation. More recently, Dr. Eliseo Perez-Stable, M.D., Director of the National Institute on Minority Health and Health Disparities (NIMHD) at the National Institutes of Health (NIH), designated people with disabilities as a distinct "health disparities population."

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.

### Suggested additions

The alternative suggestion for the new mission statement should read "To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to enhance health, optimize function, and prevent or reduce illness for all people."

### Suggested deletions

No response.

### Response 441

### **Reflects Strategic Plan**

Yes, the goals are reflected in the statement and could be improved to embody the objectives and themes.

#### Suggested additions

Language that could be added to the proposed mission statement: "across their lifespan" as edited below.

"To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to optimize health for all people across their lifespan."

The NIH embodies research centers and funds research activities that span the life of all people from children, adolescents, adults, men, and women from diverse backgrounds and health status. Adding this language will emphasize the NIH's commitment to understanding, prevent, and reduce illnesses at all stages of life. Because some disabilities present themselves at a later stage in life this addition will cover such cases. This will also reflect a commitment and consideration for women's health with key stages that affect women's health in general with changes across their lifespan (menstruation, pregnancy, menopause, etc.).

# Suggested deletions

Language that could be removed is "and prevent or reduce illness" and could be modified as suggested below.

"To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to optimize health for all people." [across their lifespan]."

The reason for this language to be removed is that the concept of optimized health has in it embedded preventing, reducing, managing illness if this is taken in a very literal context. The optimization of health also includes using every resource and implementing policies that promote health in the workplace and in the training of the next generation of scientists, physicians and workforce in general. Optimizing health also takes into account mental, physical, emotional health equity, a more holistic approach not limited to illness or disease but rather well-being of all people. The suggested language "and prevent or reduce illness" here suggests that these are options. Optimizing health includes both prevention and reducing disease burden all together.

# Response 442

# **Reflects Strategic Plan**

No response.

# Suggested additions

No response.

# Suggested deletions

The [organization redacted] applied three principles to our assessment of the proposed NIH Mission Statement: (1) use language understandable to laypeople; (2) be succinct without loss of essential meaning; and (3) reflect the full body of NIH intramural science, extramural research support, and other activities. The proposed Statement raised concerns for all three principles, particularly brevity and comprehensibility to laypeople.

The [organization redacted] recommendations on the wording of the proposed Statement are to:

 Replace "fundamental knowledge about the nature and behavior of living systems" with "knowledge."

- Consider replacing "apply" with "use" and "optimize" with "improve" in the phrase "to apply that knowledge to optimize."
- Retain "health and prevent or reduce illness for all people."

The rationale for each of these recommendations follows.

The phrase "fundamental knowledge about the nature and behavior of living systems" was assessed as lengthy and likely unclear to many laypeople. There was consensus that laypeople were unlikely to comprehend the subtle meaning intended by terminology such as "fundamental," "nature and behavior," and "living systems." Some [organization redacted] members expressed concern that the phrase may inadvertently emphasize basic science and minimize other research conducted at or supported by NIH. For example, "living systems" appears to exclude the generation of knowledge about other types of complex systems, such as care delivery, social networks, and communities. The current "NIH-Wide Strategic Plan Framework," particularly the infographic on page vii, provides an opportunity to articulate the breadth and depth of NIH activities in a more comprehensive manner. Thus, the [organization redacted] recommends that the phrase "fundamental knowledge about the nature and behavior of living systems" be replaced by "knowledge."

Although [organization redacted] members expressed varying degrees of concern about the use of the words "apply" and "optimize," we were unable to achieve consensus on a recommendation. Some assessed the term "apply" as less central to the NIH mission than of other federal agencies (e.g., CDC and CMMI) and other stakeholders (e.g., clinicians, health care organizations, insurers, and the pharmaceutical industry). Some considered it integral to NIH's mission to not only seek discovery of new knowledge, but also to study the application of that knowledge to ensure public benefit. Some consider the term "seek knowledge" to encompass both new discovery and application. Initial concerns about the ability of lay audiences to understand the term "optimize" were heightened when the [organization redacted] was unable to agree on an interpretation of the word. Some members preferred the simpler term "improve," with others assessing that term as incremental rather than aspirational. The latter group of members felt that "optimize" implied striving for the best possible health for individuals whose baseline varies (e.g., younger versus older). The [organization redacted] elected to recommend further consideration of the wording of this phrase in the hopes of emphasizing the need for careful examination of related comments submitted in other RFI responses.

The terms "health" and "all people" generated much discussion around two points: (1) whether "health" includes quality of life, an important goal of research supported or done by NIH and (2) whether "all people" does or should refer specifically to those in the US or indicate a global focus. The result of this conversation was that any information gain from being more specific would be offset by length and wording that would decrease comprehension by audiences.

Ultimately the [organization redacted] coalesced around the following revision that aligned with the principles we used to assess the proposed NIH Mission Statement in the RFI: To seek knowledge to optimize health and prevent or reduce illness for all people.

We believe this succinct statement reflects the breadth of NIH activities. Importantly, the lay public may find our revision more understandable, as reflected by a substantially lower reading score than the version proposed in the RFI (e.g., Flesch Kincaid Grade Level 6.73 versus 14.29, respectively).

We appreciate the opportunity to provide input on the proposed revision to the NIH Mission Statement.

# Response 443

### **Reflects Strategic Plan**

No response.

#### Suggested additions

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

#### Suggested deletions

No response.

## Response 444

#### **Reflects Strategic Plan**

The majority of the goals and objectives within the NIH-wide strategic plan are consistent with the proposed revised mission statement. However, we recommend that the agency update any language in the strategic plan that mirrors the current mission statement. For instance, in the "Preventing Disease and Promoting Health" section, there remains language that mentions preventing disability. The NIH should update this and any other language that has ableist connotations.

Additionally, we encourage the NIH to collaborate with the Subgroup on Individuals with Disabilities and UNITE on updating the strategic plan to adhere to the proposed revised mission statement.

#### Suggested additions

The [organization redacted] recommends the NIH remove "optimize health" as it could still be interpreted as ableist, and difficult to define. Instead, we suggest replacing "optimize health" with "enhance health" or similar language.

#### Suggested deletions

The [organization redacted] recommends the NIH remove "optimize health" as it could still be interpreted as ableist, and difficult to define. Instead, we suggest replacing "optimize health" with "enhance health" or similar language.

### Response 445

#### **Reflects Strategic Plan**

No response.

#### Suggested additions

On behalf of the [organization redacted], 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 seg. 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 secondguess 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.

### Suggested deletions

No response.

# Response 446

### **Reflects Strategic Plan**

The [organization redacted] welcomes a new mission statement to address the previous statement's issue with ableism and to better reflect the goals and objectives of the NIH. However, while the proposed statement addresses the concern with ableism, it does not fully reflect the goals and objectives of the NIH as outlined in the Strategic Plan. The new statement falls short of the agency's strategies to "understand biological and environmental factors that contribute to human health and disease [1]." For the reasons below, we recommend modifying the statement to better capture the innovative advances in experimental approaches being supported and prioritized by the NIH, and to unequivocally

state the application to human health as the overarching goal of the agency's strategy. (As requested, our suggested revisions to the new mission statement are described in the following section.)

Over the last 15 years, the NIH has increasingly supported research using nonanimal methods, also called new approach methods, novel alternative methods, or NAMs, which comprised nearly 8% of nonclinical competitive awards in 2021 [2]. Based in human biology, NAMs provide important human and clinically relevant insights [3–5]. As stated in "Objective 1: Advancing Biomedical and Behavioral Sciences" of the NIH-Wide Strategic Plan for Fiscal Years 2021–2025: "Therapeutic development for many human diseases and conditions could become faster and more accurate due to the expanding use of tissue chips [1]." Indeed, through high-level efforts to catalyze the broader development and use of NAMs—like the National Center for Advancing Translational Sciences Tissue Chip projects and initiatives, the activity of the Advisory Committee to the Director Working Group of Novel Alternative Methods, and the potential Complement-ARIE program—the NIH and the researchers it funds are pioneering technological advances in cell and tissue engineering. In turn, "NIH is acting to reduce the number of animals needed for research by using [these] approaches [1]."

In addition, a major focus of the NIH-Wide Strategic Plan for Fiscal Years 2021–2025 is understanding and addressing the social determinants of health and causes of health disparities, factors that cannot be studied using animals. As stated in Objective 1: "Building the foundation for science includes constructing an overall picture of how physiological, behavioral, and social factors alone and in combination may determine human health [1]." One of the crosscutting themes of the Strategic Plan is "Improving Minority Health and Reducing Health Disparities," which states NIH's commitment "to supporting a robust program of research examining how biological, behavioral, environmental, socio-cultural, and other factors interact with and shape individuals' health trajectories across the lifespan [1]." These research aims require investigating patient communities, populations, and environments—contexts not captured by the mission statement terminology, "living systems."

Lastly, the Strategic Plan makes it clear that foundational science "lay[s] the groundwork for important future advances that with improve the nation's health [1]." The ultimate application of fundamental knowledge gained through NIH-funded research is human health interventions. This is further made clear again in the Strategic Plan: "NIH supports the creation of foundational data resources that enable basic research and improve understanding of the biological and environmental factors that contribute to human health and disease [1]." As it is made so clear in the Strategic Plan, the focus on human health, human biology, human behavior, and human environments should be explicitly stated in the mission.

Accordingly, the 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," does not accurately reflect the goals and objectives as outlined in the NIH-Wide Strategic Plan for Fiscal Years 2021–2025. "Living systems" neither captures the multitude of complex, innovative in vitro and in silico approaches the NIH increasingly supports, nor does it capture the non-living systems and structures of human environments and social contexts that impact health and that crosscut all aspects of the NIH's Strategic Plan; and nowhere in the statement is human health or biology mentioned.

(References at end of comment.)

# Suggested additions

For the reasons above—to reflect the NIH's commitment to pioneering innovative in vitro and in silico approaches and to understanding and addressing the social and environmental determinants of human health—the [organization redacted] recommends further revising the mission statement as follows:

"To seek fundamental knowledge about human biology, behavior, and environments and to apply that knowledge to optimize human health and prevent or reduce illness for all people."

This statement replaces "the nature and behavior of living systems" with "human biology, behavior, and environments," and it adds "human" as a descriptor of "health." This language more accurately reflects the non-living systems that the agency increasingly supports (i.e., tissue chips); the socio-environmental factors that impact human health and that are pillars of the agency-wide strategy; and the overarching goal of NIH research to understand and improve human health.

### References

1. U.S. National Institutes of Health. NIH-Wide Strategic Plan Fiscal Years 2021–2025. 2020. Available: https://www.nih.gov/sites/default/files/about-nih/strategic-plan-fy2021-2025-508.pdf

2. Chang H, Jorgenson L. Proposed ACD Novel Alternative Methods Working Group. 125th Meeting of the Advisory Committee to the Director (ACD) National Institutes of Health; 2022 Dec 8. Available:

https://www.acd.od.nih.gov/documents/presentations/12082022\_Proposed\_ACD\_Novel\_Alt ernative.pdf

3. Franzen N, van Harten WH, Retèl VP, Loskill P, van den Eijnden-van Raaij J, IJzerman M. Impact of organ-on-a-chip technology on pharmaceutical R&D costs. Drug Discov Today. 2019;24: 1720–1724. doi:10.1016/j.drudis.2019.06.003

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doi:https://doi.org/10.1002/advs.202002030

5. Loewa A, Feng JJ, Hedtrich S. Human disease models in drug development. Nat Rev Bioeng. 2023; 1–15. doi:10.1038/s44222-023-00063-3

# Suggested deletions

No response.

# Response 447

### **Reflects Strategic Plan**

No response.

### Suggested additions

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.

So that the alternative suggestion for the new mission statement could be "To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to enhance health, optimize function, and prevent or reduce illness for all people."

### Suggested deletions

No response.

## Response 448

## **Reflects Strategic Plan**

Omit.

## Suggested additions

We propose replacing "living systems" with "humans" in the NIH's revised mission statement so that it reads: "To seek fundamental knowledge about the nature and behavior of humans and to apply that knowledge to optimize health and prevent or reduce illness for all people." For the NIH to achieve its goals in the latter part of the mission statement ("optimize health and prevent or reduce illness for all people"), the agency must move away from experiments on other animals, which do not provide the relevant, reliable, or translatable fundamental knowledge that is necessary to achieve these goals.

The last available estimate (2012) indicates NIH spends roughly 47% of its annual budget on experiments on animals (https://www.nap.edu/read/13322/chapter/4#23). In 2023, the agency is actively funding experiments on animals in areas where their use has led to no meaningful improvements in human health, such as sepsis and neurodegenerative disease. Across the board, experiments on animals have a low rate of translation to humans, with NCATS reporting that 95% of human clinical trials for new drugs fail (https://ncats.nih.gov/research/research-activities/ntu), despite having gone through safety and efficacy testing in animals.

While the NIH has increased its investment in human-relevant in vitro methods such as tissue chips, this investment remains paltry in comparison to its funding of animal-based experimentation. In fact, the agency appeared to double-down on its outdated support of animal models by shrouding what could be an innovative new program to replace animal use with a title that explicitly centers on the continued use of animals, and relegating human-relevant methods to a "complementary" status.

(https://commonfund.nih.gov/complementarie/strategicplanning).

According to a November 2023 Pew Research poll, Americans' trust in science has declined in recent years (https://www.pewresearch.org/science/2023/11/14/americans-trust-inscientists-positive-views-of-science-continue-to-decline/). Thirty-nine percent of respondents think that the U.S. is losing ground in scientific achievement, compared to the rest of the world (45% believe it is staying the same; only 14% think it is gaining ground). This could be attributed in part to the U.S.' inexplicable, unprogressive attitude toward more advanced, human-based methods. Compared to the U.S., other countries have made a more substantial push to move away from animal use toward human-relevant methods. For example, the Netherlands created the Transition Programme for Innovation without the use of animals (TPI), which aims to bring together stakeholders and offer a platform for identifying and developing activities to increase the pace of the transition toward animalfree innovation (https://www.animalfreeinnovationtpi.nl/). In 2021, members of the European Parliament almost unanimously supported a motion for a resolution calling on the European Commission to develop an action plan—with a timeline and milestones—to phase out experiments on animals and accelerate the transition to innovation without the use of animals in research, regulatory testing, and education

(https://www.europarl.europa.eu/doceo/document/TA-9-2021-0387\_EN.html).

Scientists with [organization redacted] have developed a common-sense strategy that NIH can implement to phase out animal use and move toward superior, non-animal methods in an evidence-based way. [Organization redacted] calls on the agency to take the following steps:

1) End animal use in research areas in which animals have been demonstrated to be poor "models" of humans and their use has impeded scientific and medical progress. Multiple reviews have documented the overwhelming failure of animal use to benefit human health in specific areas, including neurodegenerative diseases, neuropsychiatric disorders, cardiovascular disease, strokes, cancer, diabetes, obesity, inflammation and immune responses, HIV/AIDS research, addiction studies, trauma research, and medical training as well as for regulatory testing. Experiments and tests on animals in these areas should be ended as soon as possible and replaced with non-animal methods.

2) Conduct systematic reviews of the efficacy of animal use to identify additional areas in which non-animal methods are available or the use of animals has failed to protect human or environmental health and can, therefore, be ended.

3) Redirect funds from animal studies to the use and development of reliable, non-animal methods. We have previously sent ideas for how this can be achieved within NIH's current structure.

4) Implement a harm-benefit analysis system for research involving animals that includes an ethical perspective and consideration of lifelong harm inflicted on animals, to be applied to all NIH intramural and extramural research.

5) Educate and train researchers in the benefits of and how to use non-animal testing approaches. Suggestions for how this could be achieved is also available in our previous correspondence.

By making NIH's mission explicit to seeking fundamental information about humans, the agency aligns itself with a more innovative, effective, and socially-acceptable research paradigm.

### Suggested deletions

We propose to remove the phrase "living systems" in the current proposed mission statement and replace it with the word "human" for the reasons listed in the previous prompt.

# Response 449

### **Reflects Strategic Plan**

Yes.

### Suggested additions

N/A

### Suggested deletions

No response.

## Response 450

### **Reflects Strategic Plan**

On behalf of the [organization redacted], we write in support of the proposed changes to the NIH Mission Statement.

[We] are encouraged by NIH's focus on addressing health disparities for people with disabilities. [Organization redacted] supports the coordinated efforts of NIH to ensure appropriate access to care for all individuals with disabilities, and see this priority reflected in the new mission statement. Our member agencies are all community based and driven by feedback from clients, generating a more effective and equitable service provision for our community members. We understand the evolution of NIH's mission statement is part of a multi-pronged approach to ensure the highest quality care for people with disabilities, including designation as a population with health disparities, new programs for research into unmet health needs for people with disabilities, and the proposed update to the regulations prohibiting disability discrimination by recipients of HHS funding.

We acknowledge that the removal of the section in the mission regarding reducing disability reflects feedback from individuals living with disabilities. In the 2022 report of the Advisory Committee to the Director, Working Group on Diversity, Subgroup on Individuals with Disabilities, authors suggest the current mission statement "could be interpreted as perpetuating ableist beliefs that disabled people are flawed and need to be 'fixed.'" Further, review of reports from the Advisory Committee to the NIH Director, informed by the Subgroup on Individuals with Disabilities, and a report from the NIMHD Working Group on Persons Living with Disabilities, as well as a review of existing research, suggest the revision of the mission statement aligns with expressed need from community members. We applaud NIH's commitment to supporting inclusivity and uplifting the voices of people with lived experience through the updating of their mission statement.

While the steps above are pivotal in advancing equity for people with disabilities, many factors influence quality of life and healthcare outcomes for this population. An outsized portion of adverse health outcomes and healthcare costs find their root in lack of access to good nutrition, which is predicated on healthcare inequities—both racial and socioeconomic. [Organization redacted] seeks to address the inequity that already exists and to rebalance health in favor of our clients through the services we provide. [Organization redacted] agencies aim to address environmental, cultural, social, and mental health factors in the way our service is delivered, continuously evolving over the last 40 years. Peer-reviewed research shows that access to MTMs leads to impressive improvement in health outcomes and reductions in healthcare costs.

Prioritizing interventions addressing unmet medical nutrition needs is another vital aspect of addressing health disparities and providing highest quality healthcare to individuals with disabilities. The MTM intervention is a disease treatment that fulfills a prescribed diet, targeting nutrition as a social determinant of health. MTMs are meals delivered to individuals of all ages living with severe or complex chronic illness(es) and limitations to activities of daily living (ADLs), as deemed necessary by a healthcare professional. Meal

plans are tailored to the medical needs of the recipient by a Registered Dietitian Nutritionist (RDN) who provides clinical nutrition care throughout the intervention.

Because of the compelling research results for MTMs, some states and healthcare plans use waivers and regulatory flexibilities to pilot coverage of MTMs. While much success has been seen in these pilots, they remain on the margins of innovation and fall short of establishing the widespread coverage needed to ensure equitable access to these critical services across the U.S. Changing healthcare policy to fund, deliver and explicitly evaluate the MTM intervention in Medicare and Medicaid would solve this issue.

[Organization redacted] applauds NIH for their important effort to advance health equity for people with disabilities and looks forward to continuous efforts to address the unmet health needs for those living with complex, chronic and severe illnesses.

#### Suggested additions

No response.

#### Suggested deletions

No response.

### Response 451

#### **Reflects Strategic Plan**

No response.

#### Suggested additions

"To understand the nature and behavior of living systems, to optimize the health of all people."

Please see the explanation in the next box.

#### Suggested deletions

"To seek fundamental knowledge" means "To understand". The latter is more thorough than "to seek knowledge" and appears more friendly to nonspecialists.

The purpose of "to seek fundamental knowledge" has always been "to apply that knowledge." Therefore the latter appears verbose.

"Optimize health" implies "prevent or reduce illness." Thus the proposed language can be more concise and artistic.

### Response 452

### **Reflects Strategic Plan**

Not addressing disability alongside illness, which are disparate in their impact on health, is inconsistent with the strategic plan. E.g., the INCLUDE program and other aspects of investigating and supporting those with disabilities, whether acquired genetically or through accident, injury, environmental causes. Likewise supporting the preservation and extension of life for all people, not mentioned in the proposed statement, would be consistent with the principles contained in the strategic plan.

### Suggested additions

The [organization redacted] proposes the following as a revised NIH mission statement.

"To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to optimize health, prevent or alleviate illness, support those with disabilities, and preserve and extend life for all people."

This proposal is inclusive, comprehensive, and recognizes the need to reduce things that degrade health, while supporting the life and health of all people.

### Suggested deletions

See above.

# Response 453

### **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. The NIH-Wide Strategic Plan emphasizes that every population should be represented in research through the Crosscutting themes, such as "improving minority health and reducing health disparities among underserved groups" (1; pg 32). Importantly, minority population representation intersects with all Crosscutting themes and the three main objectives (1; pg vii). As the Strategic Plan states, the purpose of Crosscutting Themes is to emphasize "[m]any scientific challenges and opportunities are not unique to any one Objective in this Strategic Plan (1; pg 32)." However, the new mission statement forgoes encompassing the spirit of the Crosscutting themes. Since a mission statement outlines an organization's guiding principles, the NIH's mission statement should include language addressing these core values. Even with broad language, this would ensure the NIH's current efforts and priorities are clear.

Also, while the proposed mission statement emphasizes seeking fundamental knowledge and applying it to improve health, it does not explicitly mention specific goals related to increasing research capacity or research conduct. As such, only the first objective of "Advancing Biomedical and Behavioral Sciences" is emphasized in the proposed mission statement. Thus, the proposed mission statement demonstrates a greater emphasis on the first objective compared to the second and third objectives. When including language on research capacity and conduct, their intersection with diversity should be addressed. In 2022, over 70% of NIH-funded principal investigators (PIs) were white (2), and only about 1% of NIH-funded PIs had a disability (3). The NIH recognizes a need for more researchers from diverse backgrounds by creating specific training programs and heavily emphasizing "the high priority that NIH places on workforce diversity" in the Strategic Plan (1; pg 17). However, the mission statement does not reflect these endeavors. In revising the mission statement and soliciting feedback, the NIH is presented with an opportunity to incorporate broad language that highlights and emphasizes ongoing efforts. Crafting a single sentence that encompasses all goals is challenging, yet the NIH's mission statement would better demonstrate the NIH-Wide Strategic Plan's intentions by emphasizing diversity in research capacity and conduct.

### References:

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

- 2. https://report.nih.gov/nihdatabook/category/25
- 3. https://report.nih.gov/nihdatabook/category/27

### Suggested additions

Our proposed mission statement: To collaborate with a diverse workforce and seek fundamental knowledge about living and built systems to optimize health, reduce disparities, and eliminate barriers for people with disease and disability.

Discussions of proposed changes are below.

### "Diverse workforce"

We propose the addition "to collaborate with a diverse workforce" to address research conduct and capacity as well as inclusiveness within these objectives (1; pg vii, pg 16-31). Despite NIH initiatives to increase diversity in their workforce, NIH data shows that several minority groups are still underrepresented in terms of funding allocation and employment at the agency (2-4). Having diverse groups of people work together contributes new perspectives and improves innovation, productivity, and inclusiveness (5,6). Further, emphasizing diversity is crucial for fostering inclusivity and addressing substantial gaps in understanding the unique health needs of minorities (7). For these reasons, we propose using "diverse workforces," not only to reflect capacity, but also conduct since consideration of diversity in partners, accountability, management, and operations is important.

### "Built systems" "Eliminate barriers"

We propose the addition of "built systems," "reduce disparities," and "eliminate barriers" into the mission statement. If included, the NIH would further demonstrate a commitment to a broad approach to health that considers biological, medical, social, and environmental factors. When disease and disability are viewed only through a medical lens, the discussion concerns how to fix the individual rather than how to address the barriers in their community (8,9). Societal and environmental barriers include, but are not limited to, difficulties in accessing healthcare services, discrimination, and lack of accommodations (9,10). These systemic barriers, amongst others, contribute to unequal access to treatments and interventions. These challenges exacerbate existing disparities, creating a cycle of inequality that hampers the well-being of affected populations. Including this language would also emphasize that systemic barriers, and strategies to surmount them, are important topics of health research.

### "Reduce disparities"

We propose adding "reduce disparities" because it aligns with the NIH's Crosscutting theme and commitment to fund research that recognizes and responds to the distinct health needs and disease burden of underserved groups (1, pg 32). Non-disabled marginalized individuals face barriers to care but also increased disease burden due to these obstacles, making the topic of disparities as broad as it is important (11). Further, healthcare disparities of marginalized individuals are often perpetuated when the identities intersect (12). A higher prevalence of disability has been reported by persons living in poverty, amongst Black, Indigenous, and people of color, and members of the LBGTQ+ community (12-15). Since the NIH funds research about health disparities (1), the mission statement would improve by mentioning this goal.

### "Disease and disability"

We appreciate the NIH's effort to respect concerns raised by health experts in the disability community by removing the phrase "reduce illness and disability." However, the recent NIH

designation of people with disabilities as a health disparity population, including disability within the NIH mission statement, advances efforts to address the healthcare needs of the largest minority group in the country (16-18). We propose using "disease and disability" as an alternative to distinguish between two broad, distinct concepts. The Centers for Disease Control and Prevention defines disease as "sickness, illness, or loss of health" (19). A prominent belief in the disability community includes disability being an identity, an experience, and a culture, separate from pathology (20,21). Differentiating between these groups and including them within the mission statement furthers the NIH-Wide Strategic Report's emphasis on disease prevention and treatment while acknowledging the societal aspects of disability (1; pg 3-15).

Furthermore, our organizations include individuals with disabilities and/or chronic illnesses as well as allies. We consist of professionals in healthcare, basic and translational research, and many other professions. Removing the term "disability" raises concerns amongst our communities due to the potential impact on public health research, policy, and accessibility in the clinical environment. NIH reports identified major gaps in disability-related data collection, such as exclusion from intervention trials and a low percentage of surveys recording disability status and type in demographic information (16,17). We hope to prevent further exclusion in all realms of research by intentional inclusion of the word "disability."

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### Suggested deletions

We suggest removing certain phrases to account for the several additions suggested in the second prompt. Here are the proposed words for removal:

### "about the nature and behavior"

We recommend removal of the language "about the nature and behavior" to increase the conciseness and readability of the mission statement. This language does not contribute as significantly to the mission statement and may be covered well under living systems.

#### "prevent or reduce illness for all people"

We recommend removal of this language because we felt that "prevent or reduce illness" could fall under optimizing health. The phrase "for all people" is redundant in the context of the statement proposed in the second prompt. It is implied that NIH aims to benefit everyone by addressing disparities and barriers faced by individuals with disease and disability. In other words, the focus on diversity and the explicit mention of reducing disparities and eliminating barriers inherently implies an inclusive approach that aims to benefit all individuals.

# Response 454

### **Reflects Strategic Plan**

Thank you for the opportunity to provide comment on the proposed change to the mission statement of the National Institute of Health (NIH). [Organization redacted]'s work is based on the knowledge that people with disabilities of varying ages, racial and ethnic backgrounds, genders, and sexual orientations are fully capable of achieving self-sufficiency and contributing to their communities with access to needed services and supports, protection from discrimination, and the reasonable accommodations and modifications enshrined in U.S. law.

The proposed change would alter the second half of the NIH's single sentence mission statement (bolded in the proposed revised mission statement) as follows:

### 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."

[Organization redacted] is in favor of the proposed change as not merely a semantic exercise, but an overdue acknowledgement of many people with disabilities who feel that their disability is inseparable from their identity and celebrate who they are. NIH's current mission statement reflects an outdated point of view which conflates disability with ill health and minimizes the health and life goals of disabled people. The proposed change broadens the NIH's mission statement from eliminating disability to allow funding and research priorities that encompass, for example, examining if and how people with functional limitations receive preventive care to determine if there are disparities in access, quality of care, and health outcomes. Similarly, the changed mission statement could support investigating the comparative effectiveness of intensive community-based treatment rather than in-patient institutionalization for adolescents who experience severe mental heath crises. These examples are not necessarily proposals that would immediately reduce disability, per se, but they could lead over time to results that optimize health and reduce illness for people with existing disabilities and chronic conditions.

As longtime advocates of disability civil rights such as Section 504 of the Rehabilitation Act, the Americans with Disabilities Act, and Section 1557 of the Affordable Care Act, [organization redacted] is familiar with the need to unearth and battle ableism, especially in healthcare where disabled people tend to be understood only through their medical diagnoses. But transforming how society perceives people with disability does not have to happen only through lawsuits and complaints. NIH's deliberate decision to reject the assumption that people with disabilities only need to have disability scrubbed out of them is a powerful affirmation of the disabled community's capacity for a well and full life. The proposed mission statement can lead to a wider embrace among researchers and clinicians of the need to address disability-related health and healthcare disparities, reject implicit disability bias, and let disabled people have the central say in what they need and want to lead healthy lives.

We anticipate that this change in the NIH's mission statement is only the beginning in a multi-step effort to fully include people with disabilities as researchers, healthcare clinicians, research subjects, and as patients and families within the work and goals of NIH. We are particularly cognizant of the need for further research and understanding of how disabled persons across the full range of race, ethnicity, gender, age, sexual orientation, and gender identity experience multiple and potentially compounded barriers to achieving optimal health and living well. We support the many strategic interventions laid out by the Advisory Committee to the Director's Working Group on Diversity, Subgroup on Individuals with Disabilities in it's December 2022 recommendations, and ask NIH to exercise its leadership and inter-agency coordination role toward swiftly achieving the key additional steps laid out in the Subgroup's report; [organization redacted] notes and applauds NIH's recent designation of people with disabilities as a health disparity population, which was one of the recommendations.

We also ask NIH to establish an accountability framework to promote progress and public transparency for each recommendation.

# Suggested additions

[Organization redacted] suggests that the NIH consider adding the starred word that has been inserted below to its proposed mission statement. Doing so allows NIH to acknowledge that scientific investigation, medical advancement, and health innovation in the U.S. has not occurred in an objective fashion that fairly benefits everyone in the country. Rather, healthcare as a practice, as a business, as an educational training ground, and even as an ideal has operated with embedded structural racism, ableism, and implicit biases that lead to excluding people who look, act, think, or function in atypical ways. For example, people with disabilities have been denied equally effective healthcare, left out of clinical trials, and not provided with needed accommodations and modifications in graduate and professional education. 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. "To \*equitably\* 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."

### Suggested deletions

No response.

# Response 455

### **Reflects Strategic Plan**

No response.

### Suggested additions

No response.

### Suggested deletions

The [organization redacted] strongly supports the proposed revision of the NIH mission statement and the efforts of the NIH to increase diversity, equity, inclusion, and accessibility (DEIA) within the biomedical research workforce. We also agree with the agency that "individuals with disabilities experience unique challenges in pursuing and maintaining biomedical research careers that may differ from the experiences of other underrepresented groups." Accordingly, we appreciate NIH's engagement with the disability community, as well as the development of the working group under the Advisory Committee to the Director (ACD working group) to identify strategies and recommendations specific to supporting researchers with disabilities.

Prior to this proposed revision, the NIH mission statement read as follows: 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.

The proposed change revises the language in accordance with the recommendations from the ACD working group to read:

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.

Clarifying that NIH's mission should not include "reducing disability" was a key conclusion of the ACD working group report, which found that the current mission statement "could be interpreted as perpetuating ableist beliefs that disabled people are flawed and need to be 'fixed." The [organization redacted] agrees with this finding, as well as statements from both NIH leadership and the co-chairs of the ACD working group that language matters, and it is important to consider how the current mission statement may impact both the science and the scientists supported by the NIH. From conversations with researchers in academic medicine who identify as part of the disability community, it is clear that this update to the mission statement is a welcome and significant change that will "acknowledge modern and community-centered views of disability." The [organization redacted] also finds the proposed language to be consistent with NIH's agency-wide strategic plan as well as the NIH plan for enhancing DEIA. We urge NIH to ensure that the revisions to the mission statement are only a step in addressing inclusivity and accessibility issues. As stated in one of the 10 key principles in the [organization redacted]'s Principles of Trustworthiness, "without action, your organizational pledge is only performance." We similarly appreciate the comments of NIH Chief Officer for Scientific Diversity Marie Bernard, MD, who stated: "updating a mission statement is just one action an organization might take to foster disability equity and inclusion. Transformative change involves identifying and addressing systemic and structural factors that may hinder the participation of people with disabilities in science."

We look forward to working with NIH as the agency implements additional recommendations of the ACD report in support of increasing support for individuals with disabilities in the research workforce. The [organization redacted] is actively working in support of many of these same goals, including integrating disability inclusion and equality into DEIA efforts, and looking at ways to improve and standardize data related to researchers with disabilities within academic medicine.

We would also like to again emphasize the importance of continued engagement with the disability community and including perspectives of individuals with disabilities in these efforts.

# Response 456

# **Reflects Strategic Plan**

We appreciate the opportunity to provide input on the revised NIH mission statement.

NIH's current mission statement 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."

The current mission statement could be interpreted as perpetuating ableist beliefs that disabled people are flawed and need to be "fixed."

Considering this, the proposed new mission statement is: "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."

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.

### Suggested additions

We suggest a proposed alternative of the new mission statement could be "To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to enhance health, optimize function, and prevent or reduce illness for all people."

### Suggested deletions

No response.

# Response 457

### **Reflects Strategic Plan**

The proposed mission statement does not reflect the goals and objectives because it does not make reference to lifespan, even though lifespan is integral in the NIH-wide strategic plan. "Lifespan" must be part of the new mission statement, as it is in the current mission statement.

### Suggested additions

I believe the new mission statement should retain the phrase "lengthen life" because living healthier longer is a universal good. It should be: "To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to optimize health, lengthen life, and prevent or reduce illness for all people."

#### Suggested deletions

None.

### Response 458

### **Reflects Strategic Plan**

Overall, the proposed mission statement addresses most of the objectives in the NIH-Wide Strategic Plan for Fiscal Years 2021–2025 but needs to address 1) does not elaborate on technological advances for treating diseases and 2) scientific integrity, accountability, and responsibility in science. The proposed mission statement addresses objective one by seeking "fundamental knowledge about the nature and behavior of living systems." The proposed mission statement does not address objective two, as there is no language on maintaining or renewing scientific research capacity. Explicit language should be included in the proposed mission statement of financial support but also inclusion of support and increased infrastructure for the diverse scientific workforce. Furthermore, the proposed mission statement should mention promoting and maintaining scientific integrity, accountability, and responsibility as they are fundamental for carrying out scientific research.

### Suggested additions

The NIH has a history of promoting the eradication and elimination of diseases and thus should include such language in its mission statement. Within the current proposed mission statement, NIH only references the "prevention and reduction of illnesses." The current language limits NIH's scientific approaches, advancements, and long-term goals to identify root causes and eradicate diseases. NIH has a history of working towards eliminating diseases, such as basic research and understanding of SARS-CoV2, notably through its RECOVER initiatives. By explicitly expanding the proposed mission statement to include "eradication," the NIH acknowledges the importance of addressing the impact and root causes of diseases. By committing to eradicating diseases, the NIH amplifies its dedication to a more transformative research approach and reinforces its initiatives of how imperative it is to eliminate diseases at their source.

Explicit language should be included in the proposed mission statement of not only financial support but also inclusion of support and increased infrastructure for the diverse scientific workforce. One of the NIH's primary functions is to give intramural support to its

researchers and extramural support to researchers nationwide. These finances are essential and critical for scientific advancements and are necessary to fund research and the workforce that works diligently to produce said research.

The proposed mission statement should also include mention of the promotion and maintenance of scientific integrity, accountability, and responsibility, as they are fundamental for carrying out scientific research and are mentioned in objective three. Since the COVID-19 pandemic, public trust in science and medicine has reached new all-time lows. As one of the significant beacons of scientific research in the United States, the NIH should lead the way and set an example in reestablishing trust with the public. For these reasons, it is critical to include in the proposed mission statement so the public knows this is an essential scientific goal.

# Suggested deletions

Within the NIH's proposed mission statement, the NIH "seeks to understand fundamental knowledge about the nature and behavior of living systems." However, the vague language of "nature and behavior" makes it unclear what components will be studied and potentially excludes how these subjects could be studied. Adopting an inclusive approach that acknowledges the critical role of molecular and genetic methodologies and advanced technological approaches will aid in gaining a comprehensive understanding of the intricate nature and dynamic behavior within living organisms. This commitment extends beyond traditional biological aspects, encompassing the depth of established knowledge and the need to leverage and promote cutting-edge technologies. Furthermore, the current language in the proposed mission statement obscures the nuanced relationship between "nature and behavior" being studied and falls under preclinical or clinical scientific sectors. Specification of this language will ensure that NIH continues to support and promote all facets of research and bridge the gap between theoretical methodologies and practical applications.

# Response 459

# **Reflects Strategic Plan**

"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."

# Suggested additions

To seek fundamental knowledge about the nature and behavior of systems, including human beings, to apply that knowledge to optimize health and reduce illness while accepting disability as a normal part of the human condition.

# Suggested deletions

There is no mention of human beings.

There is no statement affirming DEI progress toward acceptance of disability as human—not illness.

# Response 460

### **Reflects Strategic Plan**

We support the proposed revised mission statement for the reasons outlined below. The proposed revised mission statement is aligned with the broad goals and specific objectives outlined in the 2021–2025 Strategic Plan. The pursuit of health optimization as described in the sub-objective "Developing and Optimizing Treatments, Interventions, and Cures" of Objective 1 "Advancing Biomedical and Behavioral Sciences" supports the evolution of treatment and individuation of patient needs for best possible outcomes. Health optimization also has implications for public health and the need to create responsive, agile systems that reduce illness for all people.

As reflected in Objective 3 and the crosscutting themes, social responsibility and the reduction of health disparities is a critical focus of this strategic plan. The current mission statement's stated goal to "reduce illness and disability" perpetuates health disparities and the false perception of disability as something to be cured and, by extension, disabled people as "broken" and in need of "fixing." This harmful narrative is one that the disability justice community has fought against for years, beginning with the rejection of eugenicist forms of institutionalization and treatment that denied autonomy and agency to people with disabilities. Creating a false equivalency between illness and disability further marginalizes people with disabilities by suggesting a separation of disability as a thing to be cured from the person living with a disability rather than a holistic and comprehensive view of the individual that includes their disability as part of their identity. Disability is a biological reality that every individual will encounter if they live long enough. The revised mission recenters the work of the NIH on health optimization and universal accessibility.

### Suggested additions

We have no additional suggestions for language that should be added to the proposed mission statement.

### Suggested deletions

We have no suggestions for language that could be removed from the proposed mission statement.

# Response 461

### **Reflects Strategic Plan**

Your commitment to prevention research extends to epigenetics, which can be modified by social phenomena. You recognize that you are collaborating with the public: thus, you are concerned with issues of equality, justice and progressiveness in the larger community (worldwide). Your cross-discipline methods even must approach spirituality as data to understand and work with. Your main thrust, I perceive, is the quest for improving and extending our tomorrow.

The acronym ARTEMIS: American Recovery Team Ecological Muse International Synthesis seems appropriate to me to express your goals; it maintains US leadership, while asserting your effort of compiling unwellness prevention practices from all over the world.

### Suggested additions

I would, instead of "apply," use "connect": apply means "administer; smooth over with a cloth; rub in; spread, smear, cover with; work in." Even in its sense of "be relevant, deal with," it means "touch." I feel that "connect" is stronger, and it expresses your aim better.

Additionally, "optimize health" indicates "prevention or reduction of illness." You don't have to repeat it there. "To seek fundamental knowledge of living systems and connect it to optimize human health," I would suggest, is your complete meaning.

#### Suggested deletions

See above.

### Response 462

#### **Reflects Strategic Plan**

No response.

#### Suggested additions

The proposed removal of the words "lengthen life" from the mission statement is concerning. While the change may seem benign, it must be considered in light of the current economic incentives and pressures in the healthcare system. The U.S. Department of Health and Human Services Office for Civil Rights recently issued a Notice of Proposed Rule Making (NPRM) (https://www.federalregister.gov/documents/2023/09/14/2023-19149/discrimination-on-the-basis-of-disability-in-health-and-human-service-programs-oractivities#p-156) detailing massive healthcare discrimination impacting people with disabilities, including older adults. The NPRM section on Denial of Treatment reported on systemic pressures to forego life sustaining care. During the early phases of the COVID-19 crisis, HHS/OCR also took action to address healthcare discrimination in treatment denial that risked death from COVID. (https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf?fbclid=IwAR351WokrC2uQLIPxDR0eiAizAQ8Q-XwhBt\_0asYiXi91XW4rnAKW8kxcog) Our organization receives calls from family members of persons being pressured to forego life sustaining treatment and even from families where treatment has been denied without prior notice or over their expressed objections under so called "futility" policies. These and other bioethics policies are the subjects of formal reports by the National Council on Disability, an independent federal agency charged with advising the President, Congress, and other federal agencies. (https://ncd.gov/publications/2019/bioethics-report-series) All of these reports document a healthcare system that all too readily writes off people as inappropriate for treatment or, in effect, "better off dead." Now is not the time to drop "lengthen life" from the NIH mission because it sends the wrong message. The language should be added back.

### Suggested deletions

No response.

# Response 463

### **Reflects Strategic Plan**

In general, [organization redacted] supports the proposed changes to the NIH mission statement. We also believe these changes reflect the goals and objectives in the NIH-Wide Strategic Plan for Fiscal Years 2021–2025.

The current NIH mission statement language emphasizes the need to "reduce" disability in order to achieve enhanced health. This harmful language perpetuates an outdated and ableist framework in which people with disabilities are viewed as defective. In health research and health care, disability has long been approached from this medical model perspective, which assumes a need to "fix" or reduce the effects of disability on individual functioning, with a near-exclusive focus on deficits and negative impacts. This language disregards the complex identities and realities of the 67 million Americans living with disabilities, and fails to acknowledge the inherent worth and dignity of their lives. It is also tied to damaging assumptions that have led to widespread implicit biases and stigma about disability in health care and research. Ableism and ableist language has long been used against people with disabilities for decades to justify segregation in institutions, discrimination in the workplace, and inequities in education. Despite the American's with Disabilities Act (ADA), people with disabilities continue to experience inequities at all levels, including the systemic and institutional levels. These inequities are only compounded when other factors such as race, age, and gender are added.

As the nation's premiere medical research agency, promoting inclusivity, and reducing stigma and bias is paramount. All people are capable of optimizing health and leading healthy lives, regardless of ability. The proposed updates to the mission statement reflect a language shift necessary to reduce negative attitudinal, structural, and policy level barriers that negatively impact the health of people with disabilities.

### Suggested additions

[Organization redacted] supports the proposed mission statement. We also suggest considering the following specific language addition of "equitably," as included below:

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

In order to optimize health and prevent or reduce illness, knowledge must be sought and applied in a way that centers equity and equitable outcomes. Health equity, by definition, "is the state in which everyone has a fair and just opportunity to attain their highest level of heath." As the NIH-WIDE Strategic Plan for Fiscal Years 2021–2025 recognizes the importance of research in addressing health disparities, [organization redacted] believes the inclusion of the term "equitably" in the mission statement will further reflect and clarify a commitment to these goals.

### Suggested deletions

[Organization redacted] does not suggest removing any language from the proposed mission statement.

# Response 464

### **Reflects Strategic Plan**

[Organization redacted] has previously urged NIH to incorporate an extremely vital component of better health, function, into its NIH-Wide Strategic Plan for Fiscal Years 2021–2025 and within its institutes' planning. The current reexamination of NIH's mission statement provides ample opportunity for NIH to recognize this overlooked gap in NIH's strategic planning and research, especially rehabilitation research, portfolio.

Acquiring and regaining function from a health challenge, provides a proven pathway for individuals to better optimize their health. In turn, better health optimization leads to an array of benefits, both physical and mental, for individuals. Inevitably, individuals will enjoy improved quality of life. In concert, independence will grow and individuals will grow more productive. Long term, medical knowledge base increased to better optimize the health needs of our nation and beyond. As a result, Health care costs should be lower and the economy should grow.

Additionally, NIH should elevate, extend and incorporate the principle of equity by including the principle in its new mission statement. By including equity in its mission statement, NIH will not only reflect the somewhat limited vision of equity included in the current Strategic Plan, but it will also encourage and engage all stakeholders, including NIH internal stakeholders, to evaluate how equity can become intrinsic to the marrow of NIH's research core operations.

### Suggested additions

[Organization redacted] suggests that NIH add the following specific language, italicized and underlined for clarity, to the proposed mission statement: "to equitably seek and apply fundamental knowledge about the nature and behavior of living systems (DELETE: and to apply that knowledge) to optimize health, function and well-being and prevent or reduce illness for all people."

By including function in NIH's mission statement, NIH will be acknowledging the rehabilitation research needs of the population it serves, the American people. As the 2021 NIH Research Plan on Rehabilitation recognizes in justifying the need for rehabilitation research, "About 26% of Americans—1 in 4 adults—have at least one disability of some kind."

Further, including function will serve as a call to action by researchers and potential researchers that rehabilitation research is a NIH-wide priority. A prioritization of rehabilitation research would serve our nation particularly well at this potentially catastrophic demographic juncture. A juncture in which not only do 1 in 4 Americans have a disability but in which the second largest generation of adults in America are aging. In fact, the aging numbers are so significant, the coming healthcare challenge has been labeled as the "silver tsunami." An ever-growing committed corps of researchers to help fill the tremendous gap in rehabilitation research to increase individuals' functional outcomes.

By including ell-being in NIH's new mission statement, NIH is aligning its mission with that of its parent agency, the Department of Health and Human Services (HHS). [Organization redacted] notes that the mission of HHS, NIH's parent agency, is in part to "enhance the health and well-being of all Americans." The benefits to the American people with a new focus by NIH on the totality of a person's health and all that well-being entails would truly optimize health for people. Again, the 2021 NIH Research Plan on Rehabilitation is instructive. In discussing rehabilitation conceptually, it speaks of the "whole person—from basic biological processes and functional impairment, to multisystem body responses, and structural changes, to assistive supports and mobility aids, and community and family integration—as well as environmental and societal supports or barriers. The goal of rehabilitation is to help all people achieve and maintain their full potential." This strikes at the heart of the fundamental building blocks of well-being. And a national commitment of research devoted to health and well-being has tremendous positive implications for the health and well-being of our nation on so many scales, economic, environmental and more equitable outcomes.

By including equity, NIH boldly recognizes the limitations of healthcare and related research of the past to serve the American people equitably. The focus should assist NIH in numerous ways to expedite the work it is already undertaking to provide more equity in aspects of health and rehabilitation research.

As the NIH-Wide Strategic Plan Fiscal Years 2021–2025 points out, NIH must continue to work to include populations across the demographic spectrum, such as people living in rural areas, women and other underrepresented and underserved populations, including the above referenced people with disabilities. The inclusion must be extended to every research avenue possible, from a diverse group of researchers, topic, participants, and stakeholders. And as former Director Francis Collins called for in his letter included in the Plan, NIH's workforce must be inclusive and equitably diverse.

### Suggested deletions

[Organization redacted] suggests that NIH add the following specific language, italicized and underlined for clarity, to the proposed mission statement: "to equitably seek and apply fundamental knowledge about the nature and behavior of living systems (DELETE: and to apply that knowledge) to optimize health, function and well-being and prevent or reduce illness for all people."

# Response 465

### **Reflects Strategic Plan**

It is interesting to me that you are no longer hoping to lengthen life. Does that imply that funding and priorities will be focused on the young?

### Suggested additions

Add: collaboration; multi-disciplinary teams; NIH leads the effort; improving quality of life as the goal. Reasons: The NIH should be viewed as driving change in our society. The researchers "seek fundamental knowledge," and the NIH serves as the catalyst for advancement. The ultimate goal should be to improve quality of life, not just prevent or reduce illness. Currently, in many cases, reducing illness comes at a very high personal cost, for example, daily GI troubles, loss of libido, loss of hair, diminished strength, etc.

"To drive collaboration and innovation in research about the nature and behavior of living systems so that diverse teams can apply that knowledge to prevent or reduce illness and improve quality of life."

### Suggested deletions

I believe that, in the proposed statement, "optimize health" is not as powerful as the phrase "improve quality of life." At the very least, I would swap them.

# Response 466

### **Reflects Strategic Plan**

We thank the National Institutes of Health (NIH) for seeking comment on its mission statement and for considering our submission.

NIH's existing mission statement conflates disability with illness and poor health—a view that is not only outdated but also ableist. Although we suggest a way to improve on NIH's proposed revision in response to Question 2, this effort appears to acknowledge this reality, and we appreciate that.

Along with this effort to revise its mission statement, as well as the laudable recent step to designate people with disabilities as a health disparity population, we encourage NIH to use its platform to lead efforts to combat the pervasive ableism that exists in the fields of medicine and research in this country, some of which NIH has an unfortunate history of being complicit in. The proposed mission statement can and should lead to a wider embrace among researchers and clinicians of the need to address disability as separate from illness, to recognize and begin to address disability-related health and healthcare disparities, to reject implicit disability bias, and to let disabled people be able to dictate what they need and desire for a healthy life. To help rectify its past harmful actions toward the disability community, NIH should continue this work intentionally and without delay.

A key element of this effort should include revising NIH's data collection and reporting efforts to more intentionally include people with disabilities, and more specifically to ensure that people with communication disabilities—including speech, hearing, and vision—are measured. This effort should also be applied to NIH grantees. We encourage NIH to report such data publicly.

# Suggested additions

Instead of the proposed revision, we believe the following formulation better reflects the NIH's intended mission, as well as its overarching goals and work:

[Organization redacted]'s Proposal: "To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge equitably to optimize the health and well-being of all people."

NIH's 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."

Existing NIH 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."

The phrase "optimize health and prevent or reduce illness for all people" is redundant. The prevention and reduction of illness and disease are essential, but the ultimate objective of NIH is to optimize the health and well-being of all people.

To help make up for the harm to marginalized communities that NIH helped contribute to, we also encourage NIH to incorporate the concept of equity into its mission statement.

### Suggested deletions

NIH's proposed revised mission statement reads: "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."

The final phrase is redundant. We encourage deleting the phrase "and prevent or reduce illness for all people," and adding "and well-being" after "health."

# Response 467

### **Reflects Strategic Plan**

The new language improves the former mission statement.

#### Suggested additions

#### Suggested revision:

To drive innovation and discovery in research about the nature and behavior of living systems and to apply them to optimize health and prevent or reduce illness and improve quality of life in all people.

#### Why?

NIH is the hope of patients and people seeking to stay well and is the largest funder of medical research—and for many patients, it is their only hope. Therefore, NIH has a responsibility to use tax payer dollars to drive innovation and seek to create collaborations that help drive it. Not just responding to applicants' ideas but inspiring researchers and innovators to push the boundaries of what we know, or think we know, and to move us forward toward what is possible (from what seems impossible).

#### Suggested deletions

Knowledge is expected at a minimum for the billions of dollars entrusted to the NIH. Therefore, NIH is expected to push the boundaries of what we know or think we know and to move toward what is thought to be impossible—to make them possible in terms of prevention, treatment, and cures.

# Response 468

### **Reflects Strategic Plan**

[Organization redacted] sees the need for NIH to include language for research as a necessary component of NIH's mission to fully encompass the strategic plan. There are multiple examples within the strategic plan highlighting the support for evidence-based scientific research. In Objective 2, the section Supporting Research Resources and Infrastructure, NIH states, "For the biomedical research workforce to succeed in moving discovery forward, it requires a scientific infrastructure that is expansive, durable, and capable of quickly integrating state-of-the-art resources that are available to all. Much of NIH's efforts in resource building focuses on providing researchers with the underlying evidence needed to design impactful research programs." In Objective 3, in section Making Evidence-Informed Decisions, NIH states, "NIH is committed to enhancing scientific

stewardship by optimizing approaches that generate evidence used to inform programmatic, operational, and policy decisions."

### Suggested additions

Specific language that could be included to the revised mission statement: "To seek applied fundamental evidence-based 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."

This added language couples funding, basic research and application to health and healthcare. NIH's funding for research is language to consider along with the supply of health research available for the public to view through the National Library of Medicine's (NLM) efforts. NLM has expanded biomedical and information systems such as PubMed and PubMed Central, ClinicalTrials.gov, GenBank, and the Sequence Read Archive which is a significant resource to public health, health research, and health technology.

### Suggested deletions

No response.

# Response 469

### **Reflects Strategic Plan**

We welcome this opportunity to impact a revision of the NIH Mission Statement. We share concerns for threats to the innate dignity of every human being, especially those with disabilities as well as marginalized persons. Such populations are very vulnerable to the growing trend at the state level to legalize physician assisted death. Thus, we recommend restoring the express goal to "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. Other federal policies have provided protection from coercion to embrace such policies, e.g., the Affordable Care Act. [Section 1553] NIH should also. Such a deletion is especially problematic considering the proposed new mission statement's deletion of "disability" as well. We understand that the deletion of "disability" itself was proposed upon the recommendation of the Advisory Committee's Subgroup on Individuals with Disability 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 considering 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. Such a

proposal, among other things, condemns and seeks 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 access to health care, and life and death. See 88 Fed. Reg. 63392, et seq.

### Suggested additions

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, since the number of persons with a disability will only increase, with the number of "Baby Boomers" aging, the threat of the potential for biases and discrimination impacting access to care is real. It cannot be ignored in public policy. While perhaps the existing terminology in the Mission Statement "to ... reduce ... disability," does seem unartful to what should be a goal, we would offer a potential alternative, such as "alleviate the impact of disability." This is a more realistic and clearly needed goal. Also, other federal policies have provided protection from coercion to embrace physician assisted death policies, e.g., the Affordable Care Act. [Section 1553]. NIH should also. Thank you for your time and consideration.

### Suggested deletions

No response.

# Response 470

### **Reflects Strategic Plan**

I write in response to the NIH Request for Information: Inviting Comments and Suggestions on Updating the NIH Mission Statement, NOT-OD-23-163 ("RFI").

NIH's current mission identifies four goals it hopes to achieve: enhance health, lengthen life, reduce illness, and reduce disability. NIH denies that its proposal to drop "reduce disability" indicates a change in priorities: it says that this merely reflects its sensitivity to the perception that this wording suggests that "disabled people are flawed and need to be 'fixed.'" I accept that statement at face value. However, NIH's RFI says nothing about why it is proposing to drop "lengthen life" from its mission statement. My comment is directed at this aspect of NIH's proposal.

For the reasons set out below, I ask NIH to modify its proposed new mission statement and maintain its commitment to lengthening life. In the alternative, I ask that NIH publicly explain why it is proposing to drop this aspect of its mission and what this change would mean to the agency's goals and priorities. I am also submitting these comment by email.

For the reasons stated, I urge NIH to maintain its current commitment to lengthening human life. This is an important goal that protects human dignity for all Americans, but most especially those with disabilities. At the very least, before NIH finalizes the proposed mission statement, it ought to state publicly why it has proposed to drop the goal of lengthening life and explain why this change in mission is in the public interest.

The proposed mission statement is out of sync with the NIH-Wide Strategic Plan because the Plan states that the NIH is committed to lengthening life, while the proposed mission statement does not repeat this commitment. The Strategic Plan in many places touts the NIH's role in developing advancements that have or promise to prevent premature deaths. Some notable examples include the following (with bold text added for emphasis):

- NIH claims that the findings from its Systolic Blood Pressure Intervention Trial have "helped change the national guidelines for treating hypertension, which . . . [i]f successfully adopted into clinical practice across the U.S., [] are expected to prevent about 107,500 deaths per year. . . ."
- The Plan also touts NIH-supported suicide prevention research, noting that "suicide remains one of the top-10 leading causes of death in the U.S., claiming the lives of more than 48,000 people each year." It notes that "NIH-supported researchers are testing brief interventions and follow-up care to prevent recurring self-harm and related comorbidities, such as substance use disorder."
- Finally, the Plan touts that NIH is "transforming treatment of sickle cell disease" with work that could offer "a cure to the approximately 100,000 people in the U.S. and 20 million globally who suffer severe pain and premature death from this condition."

As I have noted, NIH has not explained why it wants to abandon its present commitment to "seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to . . . lengthen life." As such, it is difficult to reach any certain conclusions about how NIH's proposal to abandon this mission would change its commitment to the aspects of the Strategic Plan highlighted above.

When NIH's current mission was fixed, the agency set its sights on four separate goals: it would seek out knowledge that would "enhance health," "reduce illness," "reduce . . . disability," and "lengthen life." Now NIH proposes to keep the first two but drop the others.

If enhancing health and reducing illness encompasses lengthening life, why has NIH listed it as a separate goal until now? If NIH is proposing to drop "lengthen[ing] life" as a goal, what does that indicate about its new priorities? Would this new mission statement affect NIH's commitment to lowering "premature deaths"? Would this affect any of the specific goals or projects from the Strategic Plan identified above?

Unfortunately, NIH offers nothing to assuage concerns its proposed mission statement raises. Without any explanation or reassurance from NIH, the public may reasonably conclude that the proposed new mission statement would signal that NIH is no longer seeking to prolong life with the same zeal and focus.

# Suggested additions

The easiest way for the NIH to address the problem identified above would be to maintain its current commitment to "lengthen life." This would affirm that NIH still believes that human life is an objective good that is worth preserving. It would also advance NIH's stated goal of rebutting the belief "disabled people are flawed" and their lives are worth less than non-disabled people.

As I noted in a recent public comment to HHS, one of the ways that disabled persons are discriminated against is in the assisted suicide context. Assisted suicide is now legal in ten states and the District of Columbia, almost all of which are under Democratic control. It would be most unfortunate if NIH were changing its mission statement in order to support, or to avoid conflict with, political allies that have legalized assisted suicide.

Though proponents of assisted suicide promise that "strict procedures" ensure that assisted suicide is only available to a small subset of the population, that is not what has happened in practice. Last year in Canada the number of assisted deaths jumped more than thirty percent, accounting for 4.1% of all deaths.

There is reason to believe that medical providers are especially likely to relax their assisted suicide protocols when patient is disabled. This concern is highlighted by a pending lawsuit in California, filed last April. A website put together by people associated with the lawsuit states the following:

In [states that have legalized assisted suicide], there is a two-tiered system of law and medicine, where a medical professional would be subject to civil and professional liability if they did not provide non-disabled people or people with non-life-threatening disabilities suicide prevention, according to the standard of care, if those people expressed a desire to harm or kill themselves in a medical setting. If those same professionals actually helped the person kill themselves by providing the means, i.e., a prescription for a lethal dose of drugs, that medical professional would also be criminally liable under manslaughter statutes for helping another person die by suicide.

People with life-threatening disabilities, however, are not afforded the same criminal, civil, and professional liability protections as everyone else where assisted suicide is on the books. When they get suicide assistance on the basis of their disability, namely the condition that is given a 6-month or less prognosis, this is treating members of a protected class in a different way than everyone else, thereby violating the anti-discrimination law that protects the civil rights and inherent equal human dignity of people with disabilities.

Additionally, last May researchers published the largest study yet of how physician-assisted suicide is carried out in people with intellectual disabilities and/or autism spectrum disorders. The study of 39 Dutch case reports over a decade yielded the following chilling results:

Factors directly associated with intellectual disability and/or ASD were the sole cause of suffering described in 21% of cases and a major contributing factor in a further 42% of cases. Reasons for the EAS request included social isolation and loneliness (77%), lack of resilience or coping strategies (56%), lack of flexibility (rigid thinking or difficulty adapting to change) (44%) and oversensitivity to stimuli (26%). In one-third of cases, physicians noted there was 'no prospect of improvement' as ASD and intellectual disability are not treatable.

As these sources show, individuals with disabilities are often pressured and coerced into preemptively ending their lives to avoid the alleged "burden" (financial or otherwise) they pose on their family or society. Assisted suicide laws may also give insurance companies perverse financial incentives to push assisted suicide as a cheaper alternative to the ongoing, expensive medical care that is often required to maintain disabled persons' quality of life. When physicians help a person commit suicide, they violate their oath to "do no harm" and corrupt the medical profession. Moreover, if NIH abandons its commitment to lengthening the lives of disabled persons, it is likely that NIH and the medical establishment more generally will stop committing resources that will help improve disabled persons' quality of life.

By retaining the goal of lengthening life, the NIH would help push back against the dangerous and incorrect belief that some people—and persons with disabilities in particular—are better off dead.

### Suggested deletions

I do not have any specific concerns with any of the goals currently stated in the NIH proposed mission statement. The concerns identified above would be best addressed by adding language to the proposed mission statement, not by removing any more language from it.

# Response 471

### **Reflects Strategic Plan**

No response.

### Suggested additions

No response.

### Suggested deletions

I am writing to strongly object to the proposal to remove "reducing disability" from the mission statement.

My son has level 3 autism that risks his safety and the safety of others because of eloping, pica, physical aggression, lack of awareness of danger, and similar characteristics and behaviors. OF COURSE it's in his best interest to research how to address these behaviors. Removing this part of the mission erases his struggles and challenges and abandons the agency's duty of care to him and those like him. Please do the responsible thing and reject the obviously untrue myth that striving to reduce disability is an attack on disabled people themselves. Continue to pursue the goal of reducing disability and maintain the current wording.

# Response 472

### **Reflects Strategic Plan**

No response.

### Suggested additions

The Advisory Committee to the Director's Working Group on Diversity Subgroup on Individuals with Disabilities has proposed that the NIH modify its mission statement. The working group proposed this change because it is concerned that the current mission statement could be read as perpetuating ableist stereotypes, as implying that people with disabilities are "flawed" and in need of "being fixed," and as ultimately calling for the elimination of people with disabilities. The new mission statement the subgroup suggests 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."

In response to this proposed mission statement, NIH Leadership has proposed a revised mission statement of their own: "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." This mission statement follows the subgroup's recommendation that the mission statement omit the aim of reducing disability. In addition, it dispenses with the explicit aim of lengthening life, and it incorporates the explicit aim of not only reducing illness but also preventing illness.

We endorse the aim of preventing illness in addition to reducing it. We also acknowledge the need to revise the NIH's mission statement to avoid ableist interpretations. For these reasons, we believe the NIH's proposed mission statement achieves several improvements.

However, it does so only by avoiding any mention of disability whatsoever. We believe this is an overcorrection. We are concerned that the proposed mission statement would preclude research into improving the lives of people with disabilities. For example, pharmaceutical treatments for people with Attention Deficit and Hyperactivity Disorder (ADHD) are well worth investigating, even if they do not optimize health, reduce illness, or prevent illness. One reason why is that they may help people with ADHD avoid premature death (e.g., car accidents). Re-incorporating language about the importance of lengthening life would help avoid this error. However, the NIH should investigate novel treatments for people with ADHD even if these treatments do not lengthen life, because they may expand the space of personal and professional opportunities available to people with ADHD. For example, they may enhance the ability of ADHD people to stay in the marriages and careers of their choice.

Likewise, new surgical techniques to repair the loss of peripheral vision owing to glaucoma would not lengthen life. Nor would they prevent illness, reduce illness, or optimize health. Even so, they should be considered within the purview of the NIH's mission.

These examples demonstrate that the NIH's mission statement must include language about lengthening life and addressing impairments that may lead to disabilities. How should this be done? The mission statement should not include the unqualified aim of reducing disabilities, for the reasons emphasized by the subgroup. Nor should it include an unqualified aim of lengthening life, because lengthening life may sometimes be worse for the patient (e.g., because it prolongs suffering associated with an untreatable terminal illness). It should instead emphasize that these should remain options when they are ethically acceptable.

### We therefore suggest the following alternative:

"NIH's mission is to seek fundamental knowledge about the nature and behavior of living systems and apply that knowledge to optimize health, lengthen life, prevent or reduce illness, and address impairments that may lead to disabilities—in ethically acceptable ways."

Like the NIH Leadership's proposed mission statement, this mission statement does not perpetuate ableist stereotypes, imply that people with disabilities are "flawed," or call for the elimination of people with disabilities. However, unlike the NIH leadership's mission statement, this mission statement would not put treatments for ADHD or glaucoma outside the purview of the NIH.

We concede that this mission statement does not explicitly rule out the permissibility of interventions that prevent or reduce disability. We believe this is as it should be. In some cases, the most ethically acceptable way to avoid disadvantages associated with a disability may be to prevent or reduce that disability. While many attempts to reduce disabilities are objectionable, we believe that whether an intervention is ethically acceptable should be evaluated on a case-by-case basis with the input of professional bioethicists. We believe

such input can be important not only in cases of interventions that reduce disabilities, but in cases that prolong life, enhance health, and prevent or reduce illness.

#### Suggested deletions

No response.

### Response 473

#### **Reflects Strategic Plan**

Good for the nih to finally stop equating disability as an illness that can be "cured." but unfortunately, changing the statement to remove all reference to "disability" also removes recognition of the unique needs of people with disabilities who are often left out of consideration on health studies and medical care. you need to emphasize those specific needs and not ignore them.

Also, healthcare rarely considers Asians at all. and when it does, it treats Asians as a monolith. this overlooks unique medical differences and waters down significant health issues and needs of different Asian racial groups. and since Pacific Islanders have diets, habits, traditions, and genetic makeup different than Asians, lumping Pacific Islander with people of Asian descent further negate and ignores the unique health care, genetics, key medical concerns of the different racial groups.

#### Suggested additions

"to optimize health, extend life, and prevent or reduce illness with emphasis to increase representation and resolve the health inequity of people with different disability, racial, ethnic, LGBTQ+, and/or pregnancy needs."

There needs to be emphasis on more inclusion and representation of the vast differences that are so often ignored or missed in research studies, medical recommendations, and approach to providing healthcare. that exclusion has created a significant health disparity especially of people who belong to more than one of these "missed" groups.

### Suggested deletions

Remove "from all people."

The generalization of the words "all" or "everyone" typically defaults to the "majority," particularly the white race, cis-male, heterosexual, under 45, and without disabilities. this approach in medical research and overall healthcare has created a significant health disparity to people who are non-white, women, LGBT+, over 45, and with disabilities. there needs to be emphasis to recognize the differences.

# Response 474

#### **Reflects Strategic Plan**

No response.

#### Suggested additions

I would like to suggest the following revision to the proposed update to the NIH Mission Statement. "To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to optimize health, physical and spiritual well-being, and prevent or reduce illness for all people."

### Suggested deletions

No response.

# Response 475

### **Reflects Strategic Plan**

The undersigned members of the [organization redacted] greatly appreciate the opportunity to provide comments on the proposed update to the National Institutes of Health (NIH) mission statement.

The [organization redacted] believes that the NIH must address systemic and structural factors that contribute to the exclusion of people with disabilities both in the scientific workforce and with respect to clinical research participation through an agency-wide culture shift. The [organization redacted] enthusiastically applauds NIH's efforts to implement this culture shift in a variety of ways, including the endorsement of the landmark recommendations from the Advisory Committee to the Director (ACD) Working Group on Diversity, Subgroup on Individuals with Disabilities, December 2022 report, new Notices of Funding Opportunities (NOFOs) for research into ableism and health disparities, and the recent designation of people with disabilities as a distinct health disparities population.

We are also pleased that NIH is prioritizing disability inclusion by proposing a new NIH mission statement that reflects this cultural shift and hope this action propels future changes throughout NIH's Institutes and Centers. The NIH's current mission statement 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." The proposed revision eliminates the phrase "reduce illness and disability" which stems from a medical model of disability and can perpetuate an ableist view of disability as a disease or condition to cure. The proposed revised mission statement would read "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."

We strongly support the removal of "reduce [...] disability" from the mission statement as one step in NIH's larger cultural shift to promote inclusivity in part by combating ableist language and beliefs. It is important to recognize that, in the large and diverse population of people with disabilities, many find identity and pride in their disability. The mission statement of the world's largest biomedical research funding agency should not undermine the disability community's right to claim their identity rather than reducing "disability" to a medical term describing a condition to be cured. This recognition and removal of ableist language will help NIH in its objectives to cultivate a diverse workforce, forge partnerships with diverse stakeholders, and focus on research that addresses the needs of underserved populations in pursuit of optimizing health, reducing illness, and reducing health disparities.

# Suggested additions

While strongly endorsing NIH's proposed removal of the phrase "reduce illness and disability" from its current mission statement, the [organization redacted] believes that NIH must continue its vital emphasis on rehabilitation and disability research as a component of optimizing health. In fact, if one key concept is missing from the revised mission statement,

it would be inclusion of research to maximize function. An individual can be considered perfectly healthy by medical metrics and still lack the ability to perform daily activities and function independently due to disability. This is the reason why the President's Commission on Consumer Protection and Quality in the Healthcare Industry debated and agreed on the following statement in their seminal final report entitled "Quality First: Better Health Care for All Americans," issued on March 12, 1998:

"The purpose of the health care system must be to continuously reduce the impact and burden of illness, injury and disability, and to improve the health and functioning of the people of the United States." [Emphasis added]

Despite ableist language involving the "burden of disability" in this report, the report establishes that the purpose of the health care system is to improve health and functioning of the people of the United States. For instance, a person who loses a lower limb in an accident may be perfectly healthy from a medical standpoint, but may have significant functional limitations if not provided with appropriate prosthetic limb care. In this manner, the concept of function is critical to the disability population and should be considered for inclusion in the revised NIH mission statement as a central aim of scientific research. We suggest NIH consider language focused on pursuing scientific advancements that improve the ability of people with disabilities to live and work in our society. We suggest the following language to reflect that outlook: "...and to apply that knowledge to optimize health and function, and prevent or reduce illness for all people." Many of our member organizations support adding this language to the mission statement as both a strategic and symbolic effort to ensure priority setting at NIH includes a focus on people with disabilities. Additionally, an even more representative mission statement would include language that captures the broader purpose of research not only for people with disabilities but all human beings. NIH may also wish to consider including the following language in its revised mission statement: "...and to apply that knowledge to optimize health and function, and prevent or reduce illness for all people in the pursuit of improving quality of life, independent living, and participation in the community." This phrase would serve to promote a fundamentally people-focused mission for NIH that includes individuals with disabilities. We greatly appreciate your consideration of our comments and NIH's ongoing efforts to advance disability inclusion across NIH's Institutes and Centers and the entire scientific workforce. We look forward to continuing to engage with NIH as the agency addresses implementation of other recommendations and offer any support that we can provide. Our member organizations strongly support the mission statement change as an essential step forward for the entire scientific community.

### Suggested deletions

No response.

### Response 476

### **Reflects Strategic Plan**

I oppose the National Institute of Health's (NIH) proposal to erase the goal of "reducing disability" from its mission.

As noted by the [organization redacted], "Disability itself is not a neutral state of identity; by its very nature it means impairment dysfunction and incapacity. This fact is mutually exclusive from the other fact at hand: individuals with disabilities have value and should not be stigmatized."

My daughter is profoundly autistic. Why in the world anyone would advocate the elimination of "reducing disability" from the core mission of the NIH is beyond me. How I would give anything to have her disability reduced, if only there were a way! This fact does not demean her or in any way degrade her humanity.

### Suggested additions

No response.

### Suggested deletions

No response.

# Response 477

### **Reflects Strategic Plan**

We have read the National Institute of Health's (NIH) proposal to erase the goal of "reducing disability" from its mission.

The ostensible purpose of this proposal is promotion of diversity, equity and inclusion (DEI) goals, specifically to "support disability inclusion" at the NIH. The internal report on which this idea is based, Advisory Committee to the Director Working Group on Diversity Subgroup on Individuals with Disabilities Report, December 1, 2022, asserts that the current mission statement "could be interpreted as perpetuating ableist beliefs that disabled people are flawed and need to be 'fixed."

This argument rests on a clear logical fallacy: it conflates "disability" with "individuals who have disabilities." Disability itself is not a neutral state of identity; by its very nature it means impairment, dysfunction, and incapacity. This fact is mutually exclusive from the other fact at hand: individuals with disabilities have value and should not be stigmatized.

It should go without saying that the goal of reducing disability, i.e., impairment, on both a population and individual level is a moral and pragmatic imperative that does not carry any animus toward individual people whose functioning is limited by their disabilities. Our collective desire to eradicate polio hardly demeans those individuals who have fallen victim to polio-caused paralysis. Our aim to reduce fetal alcohol spectrum disorder, and all the disability it can entail, does not mean we believe those affected are morally flawed, or flawed in the sense of any abstract philosophies. Wanting to reduce these and countless other impairments that reduce functioning and human potential — multiple sclerosis, ALS, schizophrenia, the list is long — hardly equates to "ableism."

When an obstetrician unwraps an umbilical cord choking a neonate, and therefore reducing the risk of lifelong impairment, is she engaging in ableism, or rather the most honorable sort of humanity? By any reasonable standard, disability should be prevented whenever possible. Laws mandating helmets and seat belts are not "ableist"; they protect the public from preventable injury and consequent disability and all the costs, burdens, pains and dependencies that result. When a pregnant woman takes folic acid supplements to reduce risk of spina bifida in her child, she is not "ableist," she is obviously taking prudent preventive measures to reduce the risk of serious impairment in her child. Countless public health campaigns and NIH efforts shine a light on the risks of smoking, to reduce the prevalence of disabling conditions such as emphysema and COPD. Was it ableist for the FDA to have banned thalidomide? The NIH-Wide Strategic Plan makes it clear that a paramount goal of NIH efforts is "to support innovative research ultimately aimed at protecting and improving human health." The word health of course encompasses reduced risks and impacts of disability.

While disability is often difficult to "fix," to borrow language of the report, the vast majority of people with disabilities would have preferred their disabilities be prevented, and if not prevented, then at least alleviated. Perhaps there are people who do not wish to have their disabilities reduced. For example, some deaf people may not wish to hear; some who are blind may not wish to see; some with paraplegia may not wish to walk. But this would be the 1%, not the 99%.

Some might argue that the mission statement's remaining phrase "prevent or reduce illness" would encompass disabling conditions but of course that is not true. For example, autism is not an illness, it is a developmental disorder rooted in abnormal early brain development that causes significant functional disability in the vast majority of cases. Due to unknown causes, this serious mental disorder now affects about 3% of U.S. children, portending catastrophic long-term consequences for our polity.

While the need to reduce autism rates has never been more urgent, the new mission statement would not-so-subtly remove any mission to reduce autism, either on an individual or population level. Who would pay the price for this erasure of mission? Americans who count on the NIH to spearhead efforts to identify causes, and also treatments to reduce its disabling impacts, which can include failure to achieve basic communication or living skills, aggression, self-injury, elopement, ingestion of inedible objects, property destruction, and of course lifelong dependency.

With this proposal the NIH threatens to jump into a foreign moral universe detached from its core duties and in conflict with its congressional mandates and the urgent needs and desires of American citizens and taxpayers. We oppose it in the strongest terms possible.

### Suggested additions

No response.

### Suggested deletions

No response.

# Response 478

### **Reflects Strategic Plan**

Please leave the mission statement alone. Reducing disability is a noble mission of any healthcare institution.

If ableism is such a problem, consider creating a different department with a different mission. Perhaps it can be called the Department of Ableism where people can go to receive care for their abilities and can be treated for their abilities so that at the end of treatment they are less functional human beings.

### Suggested additions

No response.

### Suggested deletions

No response.

# Response 479

### **Reflects Strategic Plan**

The [organization redacted] appreciates the opportunity to comment on the National Institutes of Health's request for input on the proposed changes to the NIH Mission Statement. It is timely and important, and we appreciate the invitation to comment.

First, we wish to commend the NIH for recognizing people with disabilities as a population with health disparities. This designation will help to ensure that people with disabilities are included in research. We also commend the NIH for launching a dedicated research program to understand the barriers, unmet needs, and necessary interventions required to address the health disparities experienced by people with disabilities.

Second, we fully endorse the proposed changes to the NIH mission statement. The current NIH mission statement speaks to "reduce illness and disability," a statement that is ableist and discriminatory. The proposed mission statement aligns with the vision and purpose of the agency. It could not be more welcome.

#### Suggested additions

No response.

#### Suggested deletions

No response.

### Response 480

### **Reflects Strategic Plan**

Please see the suggested revision options to the NIH mission statement:

- 1. "Translating biomedical and behavioral research discoveries into greater health for all"
- 2. "Translating scientific research discoveries into greater health for all"
- 3. "Transforming biomedical and behavioral research discoveries into greater health for all"
- 4. "Transforming scientific research discoveries into greater health for all"

These suggestions are made to emphasize the importance of a concise and clear mission statement that includes all lives—humans and animals involved in the research process along with those who benefit from the application of said research.

#### Suggested additions

No response.

#### Suggested deletions

No response.