

Share your ideas on Lived Experience Engagement in Science

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NINDS wants to hear from scientists and science partners about their impressions of the inclusion of lived experience engagement in the process of scientific discovery.

Lived experience engagement in this context includes bi-directional, mutually impactful interactions between scientists and science enablers and people who have lived experience of neurological conditions including those diagnosed, pre-manifest, recovered, caregivers, families and advocates as well as representatives of the deceased.

This 5 minute engagement activity asks you to share your ideas and rank the value of ideas. There are no questions asking for personal or identifying information and therefore we won't follow up with you directly. All questions are optional.

If this form is not compatible with your communication technology please email Rebekah.Cortew@nih.gov for an alternative.

1. Which best describes your position?

- faculty - clinical research
- faculty - basic or translational research
- scientist or staff - clinical research
- scientist or staff - basic or translational research
- trainee - clinical research
- trainee - basic or translational research
- Other

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Page 1 of 4

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NOTE for OMB review: Questions 2-9 will have slight wording modifications depending on the responders' answers to question 1, which identifies what area of research is most relevant to the responders' profession. The first set of screenshots show the questions as worded for basic and translational researchers. The additional screenshots provide the slightly modified questions for responders who are clinical researchers or other types of science professionals.

Inclusion of Lived Experience Engagement in Basic and Translational Research

Lived experience engagement (in this case scientists engaging with people with lived experience of a relevant neurological condition) can take many different forms including: working closely with a disease focused advocacy group, listening sessions with people with lived experience, co-development of research plans, sharing your research with relevant communities, inclusion of people with lived experience on planning committees for events and projects, etc.

2. What are the biggest obstacles to including lived experience engagement in the basic science and translational research processes? From your own experiences and what you have observed in your field, rank the examples below. Use the arrows to move the most impactful and relevant obstacles to the top.

lack of time

superiors/institution do not recognize or reward it

funders do not value it

lack of training on how to do it

difficulty finding and connecting with people with lived experience

it's not relevant to the science

it's not valued professionally

it does not positively impact the scientific outcome

lack of guides, materials or instructions to follow

lack of universally accepted metrics for evaluating engagement

3. Are there additional obstacles (not listed above) to including lived experience engagement in research? Please share.

Enter your answer

4. What incentives are most valued for scientists to include lived experience engagement in the basic science and translational research processes? From your own experiences and what you have observed in your field, rank the examples below. Use the arrows to move the most impactful and relevant incentives to the top.

improves the science by offering a different perspective

improves the lives of people with lived experience of neurological conditions

meaningful and affirming for scientists

helps scientists communicate the value of their work to broader audiences

makes a case for funding

improves the science by providing focus and goals

justification for the work from a social justice perspective

makes a case for more research to policy makers

adds to my organization's mission of connecting with the public



5. Are there additional incentives (not listed above) for including lived experience engagement in research? Please share.

6. Vote on the best description of how the inclusion of lived experience engagement by scientists is valued (by individual labs, academic institutions, companies, funding sources).

- not valued - it is very rarely mentioned or recognized
- occasionally valued - it is sometimes mentioned and recognized
- moderately valued - it's recognized occasionally and encouraged
- strongly valued - there is guidance, resources and strong encouragement for lived experience engagement in science
- valued and required - there are requirements for including the lived experience or patient perspective
- I don't know
- Other

7. Do you have specific examples or ideas of how individual labs, academic institutions, companies, or research funding sources can encourage the inclusion of lived experience engagement in research processes? Please share specific programs, activities, processes, regulations etc. from your own experience, those you've seen, or new suggestions.

8. Rank the value of the ideas for encouraging more lived experience engagement in science. Use the arrows to move the most valuable ideas to the top.

- More training is needed for scientists and health professionals on lived experience engagement (including who to connect with and how to engage effectively)
- Training is needed for people with lived experience of neurological conditions on the scientific process and how to navigate the scientific world
- Funding is needed for lived experience engagement
- Lived experience engagement should be recognized as a valuable professional activity
- Research journals, academic institutions and/or funding agencies should require some sort of lived experience engagement
- Increased awareness is needed within the research community of the mutual benefits of this engagement for scientists, research quality and outcomes, and people with lived experience

9. Do you have additional ideas about "engaging with people with lived experience of neurological conditions to improve the scientific enterprise"? Please share.

Share your ideas on Lived Experience Engagement in Science

 Thanks!

Thank you for participating in the Inclusion of Lived Experience Engagement Poll. The input we receive will inform our efforts to our efforts to facilitate lived experience engagement in research. If you have any questions about the poll or NINDS lived experience engagement efforts email rebekah.corlewi@nih.gov. Thank you!

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Inclusion of Lived Experience Engagement in Clinical Research

Lived experience engagement (in this case scientists engaging with people with lived experience of a relevant neurological condition) can take many different forms including: working closely with a disease focused advocacy group, listening sessions with people with lived experience, co-development of research plans, sharing your research with relevant communities, inclusion of people with lived experience on planning committees for events and projects, etc.

2. What are the biggest obstacles to including lived experience engagement in the clinical research processes? From your own experiences and what you have observed in your field, rank the examples below. Use the arrows to move the most impactful and relevant obstacles to the top.

lack of time
superiors/institution do not recognize or reward it
funders do not value it
lack of training on how to do it
difficulty connecting to people with lived experience
it's not relevant to the work
it's not valued professionally
it does not positively impact project outcomes
there are no resources to help guide the engagement
lack of universally accepted metrics for evaluating engagement

3. Are there additional obstacles (not listed above) to including lived experience engagement in research? Please share.

Enter your answer



4. What incentives are most valued for scientists to include lived experience engagement in the clinical research processes? From your own experiences and what you have observed in your field, rank the examples below. Use the arrows to move the most impactful and relevant incentives to the top.

improves the science by offering a critical perspective

improves the lives of people with lived experience of neurological conditions

meaningful and affirming for scientists

helps scientists communicate the value of their work to broader audiences

makes a case for funding

improves the science by providing focus and goals

justification for the work from a social justice perspective

makes a case for more research to policy makers

adds to my organization's mission of connecting with the public

builds community trust of science and healthcare systems

5. Are there additional incentives (not listed above) for including lived experience engagement in research? Please share.

Enter your answer

6. Vote on the best description of how the inclusion of lived experience engagement by scientists is valued (by individual labs, academic institutions, companies, funding sources).

- not valued--it is very rarely mentioned or recognized
- occasionally valued--it is sometimes mentioned and recognized
- moderately valued--it's recognized occasionally and encouraged
- strongly valued--there is guidance, resources and strong encouragement for lived experience engagement in science
- valued and required--there are requirements for including the lived experience or patient perspective
- I don't know
- Other

7. Do you have specific examples or ideas of how individual labs, academic institutions, companies, or research funding sources, can encourage the inclusion of lived experience engagement in the research processes? Please share specific programs, activities, processes, regulations etc. from your own experience, those you've seen, or new suggestions.

Enter your answer

8. Rank the value of the ideas for encouraging more lived experience engagement in science. Use the arrows to move the most valuable ideas to the top.

More training is needed for scientists and health professionals on lived experience engagement (including who to connect with and how to engage effectively)

Training is needed for people with lived experience of neurological conditions on the scientific process and how to navigate the scientific world

Funding is needed for lived experience engagement

Lived experience engagement should be recognized as a valuable professional activity

Research journals, academic institutions and/or funding agencies should require some sort of lived experience engagement

Increased awareness is needed within the research community of the mutual benefits of this engagement for scientists, research quality and outcomes, and people with lived experience



9. Do you have additional ideas about "engaging with people with lived experience of neurological conditions to improve the scientific enterprise"? Please share.

Enter your answer

Back

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Page 3 of 4

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Inclusion of Lived Experience Engagement in science support and science adjacent work

Lived experience engagement (in this case science support professionals engaging with people with lived experience of a relevant neurological condition) can take many different forms including: working closely with a disease focused advocacy group, listening sessions with people with lived experience, co-development of program plans, sharing your work with relevant communities, inclusion of people with lived experience on planning committees for events and projects, etc.

2. What are the biggest obstacles to including lived experience engagement in work that supports science? From your own experiences and what you have observed in your field, rank the examples below. Use the arrows to move the most impactful and relevant obstacles to the top.

- lack of time
- superiors/institution do not recognize or reward it
- funders do not value it
- lack of training on how to do it
- difficulty finding and connecting with people with lived experience
- it's not relevant to the work
- it's not valued professionally
- it does not positively impact the outcome
- lack of guides, materials or instructions to follow
- lack of universally accepted metrics for evaluating engagement

3. Are there additional obstacles (not listed above) to including lived experience engagement in science support and science adjacent work? Please share.

Enter your answer

4. What incentives are most valued for science support professionals to include lived experience engagement in their work? From your own experiences and what you have observed in your field, rank the examples below. Use the arrows to move the most impactful and relevant benefits to the top.

improves outcomes by offering a different perspective

improves the lives of people with lived experience of neurological conditions

meaningful and affirming for science support and science adjacent professionals

helps science support/ science adjacent professionals communicate the value of their work to broader audiences

makes a case for funding

improves science by providing focus and goals

justification for the work from a social justice perspective

makes a case for more research to policy makers

adds to my organization's mission of connecting with the public

builds community trust of science and healthcare systems

5. Are there additional incentives (not listed above) for including lived experience engagement in science support and science adjacent work? Please share.

Enter your answer

6. Vote on the best description of how the inclusion of lived experience engagement by science support and science adjacent professionals is valued (by organizations, academic institutions, companies, funding sources).

- not valued--it is very rarely mentioned or recognized
- occasionally valued--it is sometimes mentioned and recognized
- moderately valued--it's recognized occasionally and encouraged
- strongly valued--there is guidance, resources and strong encouragement for lived experience engagement in science
- valued and required--there are requirements for including the lived experience or patient perspective
- I don't know
- Other

7. Do you have specific examples or ideas of how organizations, academic institutions, companies, or research funding sources, can encourage the inclusion of lived experience engagement in science support and science adjacent work? Please share specific programs, activities, processes, regulations etc. from your own experience, those you've seen, or new suggestions.

Enter your answer

8. Rank the value of the ideas below for encouraging more lived experience engagement in science. Use the arrows to move the most valuable ideas at the top.

- More training is needed for scientists and health professionals on lived experience engagement (including who to connect with and how to engage effectively)
- Training is needed for people with lived experience of neurological conditions on the scientific process and how to navigate the scientific world
- Funding is needed for lived experience engagement
- Lived experience engagement should be recognized as a valuable professional activity
- Research journals, academic institutions, and/or funding agencies should require some sort of lived experience engagement
- Increased awareness is needed within the research and scientific community of the mutual benefits of this engagement for quality and outcomes

9. Do you have additional ideas about "engaging with people with lived experience of neurological conditions to improve the scientific enterprise"? Please share.

Enter your answer

Back

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Page 4 of 4

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