

Summary of Responses

Request for Information: NIH Research Plan on Rehabilitation for Fiscal Years 2021-2026

(NOT-HD-19-006)

August 28, 2019

The purpose of the Request for Information (RFI) was to solicit feedback on the community's perception of progress on priorities set in the 2016 NIH Research Plan on Rehabilitation, to set the direction and focus of the revision of the research plan, and to solicit priorities for NIH to consider including in the revised plan. The notice was published on April 23, 2019, to obtain input and was open for public comment through June 17, 2019. The questions included in the RFI were proposed by the Trans-NIH Medical Rehabilitation Coordinating Committee (MRCC) during their recurring monthly meeting.

In the RFI, the MRCC expressed interest in receiving input on the research priorities for the next five fiscal years. In the preamble, the MRCC provided a brief overview of progress on the priorities in the previous research plan and solicited input as follows:

Request for Information: Research Plan on Rehabilitation

Notice Number: NOT-HD-19-006

Key Dates

Release Date: April 23, 2019

Response Date: June 17, 2019

Related Announcements

[NOT-HD-15-032](#)

Issued by

Eunice Kennedy Shriver National Institute of Child Health and Human Development ([NICHD](#))

National Center for Complementary and Integrative Health ([NCCIH](#))

National Cancer Institute ([NCI](#))

National Eye Institute ([NEI](#))

National Institute of Arthritis and Musculoskeletal and Skin Diseases ([NIAMS](#))

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National Institute on Deafness and Other Communication Disorders ([NIDCD](#))

National Institute of Diabetes and Digestive and Kidney Diseases ([NIDDK](#))

National Institute of Neurological Disorders and Stroke ([NINDS](#))

National Institute of Nursing Research ([NINR](#))

Purpose

The *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD), National Center for Medical Rehabilitation Research is inviting comments and suggestions to guide the revision of the Research Plan on Rehabilitation on behalf of the Trans NIH Medical Rehabilitation Coordinating Committee.

Background

In 2016, the National Institutes of Health published the Research Plan on Rehabilitation which outlined the priorities of the Institutes and Centers to advance rehabilitation science

(https://www.nichd.nih.gov/sites/default/files/publications/pubs/Documents/NIH_ResearchPlan_Rehabilitation.pdf).

Since that time, the NIH promoted multiple initiatives, workshops, and funding opportunities aimed at advancing the

priorities within the research plan. Moreover, the National Center for Medical Rehabilitation Research at the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development presented annual updates on the changes in the portfolio following the publication of the research plan to the National Advisory Board for Medical Rehabilitation Research (<https://www.nichd.nih.gov/about/advisory/nabmrr>).

Information Requested

The NIH Medical Rehabilitation Coordinating Committee is beginning the update to the research plan, as required by the 21st Century Cures Act (42 USC 285g-4), and is seeking guidance from the community of stakeholders involved in this research. Specifically, the NIH requests feedback on the following:

- The community's perception of progress towards achieving the priorities specified in the research plan,
- Potential priorities or areas of research to consider in the update of the research plan,
- Current priorities that should be retained and continued,
- Emerging areas of science that will impact the research plan on rehabilitation,
- Potential focus areas for concentrated work in medical rehabilitation research.

The feedback garnered from this request for information will be reported at the May 2019 meeting of the National Advisory Board on Medical Rehabilitation Research and will be incorporated into the update of the Research Plan on Rehabilitation that is planned for 2021.

How to Submit a Response

All comments must be submitted electronically to Rehabilitation1@mail.nih.gov.

Responses (no longer than 300 words in Microsoft Word or PDF format) must be received by 11:59:59 (ET) by the response date noted above. ***Please indicate "RFI Response" in the subject line of the email.*** You will receive an electronic confirmation acknowledging receipt of your response.

Responses to this RFI are voluntary. Do not include any proprietary, classified, confidential, trade secret, or sensitive information in your response. The responses will be reviewed by NIH staff, and individual feedback will not be provided to any responder. The U.S. Government will use the information submitted in response to this RFI at its discretion. The U.S. Government reserves the right to use any submitted information on public NIH websites, in reports, in summaries of the state of the science, in any possible resultant solicitation(s), grant(s), or cooperative agreement(s), or in the development of future funding opportunity announcements.

This RFI is for information and planning purposes only and shall not be construed as a solicitation, grant, or cooperative agreement, or as an obligation on the part of the Federal Government, the NIH, or individual NIH Institutes and Centers to provide support for any ideas identified in response to it. The Government will not pay for the preparation of any information submitted or for the U.S. Government's use of such information. No basis for claims against the U.S. Government shall arise as a result of a response to this request for information or from the Government's use of such information.

Inquiries

Please direct all inquiries to:

Alison N. Cernich, PhD
Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)
Telephone: 301-496-0295
Email: Rehabilitation@nih.gov

Responses

As of June 17, 2019, the MRCC received a total of 29 responses. Comments were submitted by individuals, researchers and academic institutions, nonprofit organizations, consumers of rehabilitation

services, and professional societies. About 55 percent were submitted on behalf of organizations and their members. Many respondents commented on more than one question.

Progress toward the priorities

In general, the responses to the RFI noted significant progress toward the priorities in the Research Plan on Rehabilitation. The NIH community received commendations on their openness to input throughout the past five years and on the improvements noted in the rehabilitation research arena at NIH. However, the community noted that the priorities as stated in 2016 were broad and specific progress toward the goals was difficult to ascertain.

Priorities to consider in the revision

Multiple respondents emphasized the need to ensure the voice of individuals with disabilities in priority setting, research oversight, and planning and execution of research projects and programs. The community noted the need to include people with disabilities more broadly in NIH studies of health, general medical conditions, and wellness. Multiple requests highlighted the importance of better understanding the day-to-day needs of individuals with disabilities, their challenges in access to care, and the impact of research efforts on their quality of life and improvement in function. Moreover, the community requested better inclusion of individuals with disabilities in the process of device development, manufacturing, and implementation.

The community prioritized adherence to the model proposed by the International Classification of Functioning, Disability, and Health (ICF), as proposed by the World Health Organization, with a focus on a biopsychosocial understanding of disability. Multiple respondents noted a need to concentrate on participation and function. Furthermore, the role of personal factors that enhance recovery (e.g., resilience) and interventions that strengthen them received attention from multiple respondents.

Across responses, the community emphasized that evidence development to support the coverage or use of rehabilitation therapies and assistive technologies is still a pressing need and more efforts are required to advance the rehabilitation evidence base. Specifically, evidence-based care models, or evidence of benefit or value of specific interventions or technologies, are a critical need for the rehabilitation community. Respondents noted that efficacy studies, comparative effectiveness research, and other clinically based studies are needed to enhance the translational impact of rehabilitation research. Multiple groups asked NIH to prioritize the study of interdisciplinary care models and their impact on person- and system-level outcomes. Though integration of traditional services received the most emphasis, a number of submissions mentioned the need to integrate adaptive fitness programs, bowel and bladder programs, and wound management as part of these care models. Finally, the community expressed a desire for emphasis in health economics as it relates to rehabilitation care across the continuum. According to respondents, this poses an interagency collaboration opportunity with the National Institute on Disability, Independent Living, and Rehabilitation Research, the Centers for Medicare and Medicaid Services (CMS), and other federal agencies.

Though the research plan on rehabilitation does not emphasize specific conditions or disorders, specific requests to further research in specific conditions appeared in the submissions. In this vein, requests for research in traumatic brain injury, spinal cord injury, and cancer rehabilitation featured prominently. Requests to better integrate the concepts of plasticity and enriched environments outside of laboratory settings, to generate evidence to support high-end and high-cost assistive technologies, and to emphasize basic science appeared in the responses received.

Current priorities to be retained and continued

Many respondents felt the current priorities were still appropriate but required updates in the details or in the relative emphasis placed on individual items.

With respect to rehabilitation across the lifespan (Goal A), pediatric rehabilitation and adaptive fitness emerged as areas of priority in the responses. Though pediatric rehabilitation is mentioned in the plan, inclusion of specific approaches or models of care for children with rehabilitation needs received emphasis. The responses pointed to the need to understand the impact of social determinants of health as related to disabling conditions in children and adolescents, including the impact on their long-term outcomes. Also, a few respondents noted the need to understand the role of rehabilitation across the lifespan, specifically in aging with a disability. The community robustly highlighted the need to elevate adaptive fitness, exercise, and nutrition as an area of emphasis. This included requests for clinical and preclinical studies on the parameters of exercise for individuals with chronic disabilities to optimize outcomes and on the effect of exercise at a molecular, tissue, system, and person level. This also reflected a need to concentrate on the health and wellness of individuals with disabilities, not just the treatment of a specific condition.

The area of community and family (Goal B) is a continuing gap, and the community requested that this goal remain a separate category. In particular, a request to elevate the priority that encourages partnerships between individuals with disabilities, caregivers, and care providers to improve care and management appeared within the responses. Other respondents emphasized the need for research on self-management approaches and the interaction of the person with the environment to impact health outcomes for individuals and caregivers, especially in chronic disability. Additionally, respondents called for a focus on the transition from rehabilitation to the community, development of community-based health and wellness interventions, and promotion of community-based partnerships to promote health and wellness. Social determinants of health as an area of focus appeared in this section as well.

Comments on the technology use and development section (Goal C) related to continued development of telerehabilitation, virtual reality, and imaging techniques. A specific request pointed to the need for continued research to support high-cost and high-technology interventions and devices.

The responses to the RFI emphasized two areas contained in research design and methodology (Goal D): strategies to address heterogeneity and an increased emphasis on dissemination and implementation science. Respondents noted the need for new methods, strategies, and approaches to address the heterogeneous nature of the rehabilitation population. This methodologic need could be addressed through new trial designs or the promulgation of new statistical methods. Inclusion of implementation science in the current plan received commendations, but many respondents requested that this become an area of emphasis to translate research findings to rehabilitation practice. In particular, respondents emphasized the use of this type of research to test models of treatment; define the dose, type, and timing of interventions; and determine who responds best to specific treatments. This need should be identified across multiple diagnostic groups (e.g., cancer, pediatrics) and by provider and patient organizations. The community expressed a desire for underserved groups to receive specific attention in this area. This request tied specifically to providing an evidence base for the provision of rehabilitation care to prevent the continued reduction in coverage of services for individuals with disabling conditions or functional limitations.

In the area of translational science (Goal E), multiple requests included a need to move to a precision medicine approach for rehabilitation and research to understand precision therapeutics as informed by genetic information from the individual. Leveraging the All of Us platform to inform this area of research appeared in these responses.

Continued support for research infrastructure and training (Goal F) figured prominently in multiple responses. There was a request to create a system that connects participants with researchers, including national networks and partnerships with disability organizations and other groups that engage with these populations. Multiple commenters expressed the need to identify consensus standards regarding assessment measures and standardization of terms and definitions. The responses emphasized promotion of use of existing data and optimization of the utilization of registries and public data sets as a continued need in the field. With respect to training programs, multiple professional organizations requested the resumption of profession-specific training programs, either for the physician-scientist, rehabilitation scientists from the allied health professions, or specialties not previously funded in targeted training initiatives, such as assistive technology and prosthetics scientists. Finally, a single request requested the elevation of a priority to recruit individuals with disabilities into the field of rehabilitation research.

Emerging areas of science

The community noted that the emergence of new technologies in biosensing, portable technologies to understand behavior and function in the real world, and new imaging techniques pose unique opportunities for the rehabilitation field. Responses included a broad request to incorporate more biologic approaches, including precision medicine, regenerative medicine, microbiome, and biomarker development methods. New techniques in neuroimaging received attention as methods to enhance diagnostics and prognostics. Given the recent emphasis on non-pharmacologic approaches to pain, respondents requested an effort to enhance the understanding of the role of rehabilitation in pain management.

Some respondents noted that there is emerging evidence that activity and participation, as defined by the ICF, are medically necessary and not simply community outcomes. This emerging area of science may require new methodologies or approaches.

Potential areas for concentrated work

There were requests for NIH to take a leadership role in interagency collaboration, especially with respect to methodology development. A number of respondents brought out the need to coordinate the scientific work with federal agencies and other organizations who set policy for rehabilitation to better integrate their needs and improve research impact. Specifically, targeted requests for NIH to work in coordination with the Food and Drug Administration to improve regulatory standards for clinical trials of rehabilitation devices and with CMS to integrate findings into policy decisions received consistent attention. In addition, many of the professional organizations in the field noted a desire to build stronger relationships with NIH to build the evidence base.

Linking the NIH rehabilitation community to other NIH programs, such as All of Us, the NIH Strategic Plan for Data Science, and other large initiatives highlighted the opportunity to ensure inclusion of populations important to rehabilitation and to leverage infrastructure for rehabilitation science.

There were parallel requests to increase the potential for implementation of the research products generated by the community. At the basic level, requests targeted incentives to develop animal models and investigations that model the human condition in the clinic. Translation of clinical trials to application

in the care setting and translation of rehabilitation interventions and methods across conditions emerged in other responses. Other commenters asked for the development of design pathways for assistive or rehabilitative technologies that involve the community of technology users (e.g., persons requiring services, individuals with disabilities, caregivers, and care providers) to increase usability, encourage interaction, and strengthen the commercialization pathway.

With respect to reporting, professional organizations requested data related to funding of rehabilitation research at NIH to reflect spending across the care continuum. This would allow stakeholders to understand the relative funding of work in acute, subacute, outpatient, and community-based programs. Finally, professional organizations requested an enhancement of multidisciplinary representation on the National Advisory Board for Medical Rehabilitation Research, specifically with respect to allied health professionals.

Conclusion

The NIH Medical Rehabilitation Coordinating Committee would like to thank all respondents for their thoughtful comments. This feedback will help to inform their deliberations related to the Research Plan on Rehabilitation and in their collaborative work.