

# **A Report from the Federal Partners Meeting of the National Institutes of Health Pathways to Prevention Workshop: Can Physical Activity Improve the Health of Wheelchair Users?**

July 28–29, 2021

## **Sponsored by:**

The National Institutes of Health Office of Disease Prevention  
The National Center for Medical Rehabilitation Research of the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development  
The National Institute of Neurological Disorders and Stroke

## **Introduction**

The Pathways to Prevention (P2P) program of the National Institutes of Health (NIH) Office of Disease Prevention (ODP) promotes the use of evidence-based practices to address complex public health issues by identifying research gaps and needs in specific topic areas. The goals of the P2P workshops are to synthesize and interpret the current evidence, identify research gaps, shape a research agenda, and develop an action plan. On December 1–3, 2020, the NIH convened the P2P Workshop: *Can Physical Activity Improve the Health of Wheelchair Users?* See Background below. This workshop was co-sponsored by the NIH ODP, the National Center for Medical Rehabilitation Research (NCMRR) of the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD), and the National Institute of Neurological Disorders and Stroke (NINDS). An independent panel from the workshop made recommendations for moving the field forward, and the workshop panel report was published on the ODP website and in the Archives of Rehabilitation Research and Clinical Translation.<sup>1</sup>

As the final step in the P2P program process, the ODP convened a meeting on July 28–29, 2021 with representatives from federal government agencies (the Federal Partners) to identify strategies to address the recommendations in the P2P workshop panel report (see Appendix A for the list of attendees). This document summarizes the discussions and action items identified at the Federal Partners Meeting.

## **Background**

Approximately 65 million people worldwide require the use of wheeled mobility devices (e.g., manual wheelchairs, motorized wheelchairs, and motorized scooters) as a result of a disabling injury or illness. The World Health Organization and the Centers for Disease Control and Prevention (CDC) have recently released guidance encouraging regular physical activity (defined as any bodily movement produced by skeletal muscles that requires energy expenditure) for children, adolescents, and adults living with a disability.<sup>2,3</sup> Yet, these recommendations are based on limited evidence on the impact of physical activity on health for people currently using or who may use wheeled mobility devices in the future (referred to as “users of wheeled mobility devices”).<sup>4</sup>

Since the population of people using wheeled mobility devices is diverse, encompassing individuals with a wide range of conditions, the review focused on three conditions commonly associated with wheelchair use representing different populations, etiologies, and pathophysiologies: multiple sclerosis (MS), cerebral palsy (CP), and spinal cord injury (SCI).

### **P2P Workshop Key Questions**

To consider the available scientific evidence on the clinical benefits and harms of physical activity for users of wheeled mobility devices, the NIH ODP, NICHD, and NINDS sponsored the P2P Workshop: *Can Physical Activity Improve the Health of Wheelchair Users?* Specifically, the workshop sought to address the following four questions:

1. What is the evidence base on physical activity interventions to prevent obesity, diabetes, and cardiovascular conditions in people who are at risk for or currently using a wheeled mobility device?
2. What are the benefits and harms of physical activity interventions for people who are at risk for or currently using a wheeled mobility device?
3. What are the patient factors that may affect the benefits and harms of physical activity in patients who are at risk for or currently using a wheeled mobility device?
4. What are the methodological weaknesses or gaps that exist in the evidence to determine benefits and harms of physical activity in patients who are at risk for or currently using a wheeled mobility device?

### **Systematic Evidence Review**

A systematic evidence review of the scientific literature, guided by the key questions, was conducted by the Pacific Northwest Evidence-based Practice Center, through a contract with the Agency for Healthcare Research and Quality (AHRQ), to facilitate the workshop discussion and was published in the Archives of Physical Medicine and Rehabilitation.<sup>5</sup> The purpose of the systematic evidence review was to summarize the literature on what is known about the benefits and harms of physical activity in people who may require a wheelchair with a focus on MS, CP, and SCI. Key findings from the review included:

- Among 168 included studies, there were 44% of enrolled participants with MS, 38% with CP, and 18% with SCI.
- Studies of participants with MS found walking ability may be improved with treadmill training and multimodal exercises; function may be improved with treadmill, balance exercises, and motion gaming; balance is likely improved with balance exercises and may be improved with aquatic exercises, robot-assisted gait training, motion gaming, and multimodal exercises; activities of daily living, female sexual function, and spasticity may be improved with aquatic therapy; and sleep may be improved with aerobic exercises and aerobic fitness with multimodal exercises.
- In CP, balance may be improved with hippotherapy and motion gaming, and function may be improved with cycling, treadmill, and hippotherapy.
- In SCI, activities of daily living may be improved with robot-assisted gait training.

*Key limitations of the review included:*

- No studies reported long-term cardiovascular or metabolic disease outcomes. The majority of evidence was rated as low strength due to small sample sizes and heterogeneity of interventions and outcomes studied.
- Evidence was lacking for many outcomes prioritized by NICHD, NCMRR, and NINDS (i.e., bladder function, decubitus ulcers, lipid panels).
- Evidence was also lacking on the role of gender, age, race/ethnicity, socio-economic status, comorbidities, and other participant characteristics that may affect physical activity.
- Adverse effects of interventions were inadequately reported.

**P2P Workshop Panel Report**

A unique feature of every P2P workshop is the involvement of a multidisciplinary, independent panel comprised of non-federal representatives who have attested that they hold no scientific or personal conflicts with the subject matter of the P2P workshop for which they have volunteered their service. Workshop panel members were vetted for potential conflicts of interest. Panel members were charged with writing the P2P workshop panel report that (1) summarized the key findings and research needs outlined in the systematic evidence review and discussed at the workshop, and (2) provided a set of recommendations to move the field forward. The P2P workshop panel report included recommendations related to the key questions (see Appendix B) and three cross-cutting themes with relevance to the topic that were not specifically captured in the systematic review or in any single presentation:

1. What Matters Most (to users of wheeled mobility devices)
2. Translation of Research into Practice
3. Research Infrastructure

**Federal Partners Meeting**

The ODP convened a meeting on July 28–29, 2021 with Federal Partners to discuss ways of addressing the recommendations contained in the P2P workshop panel report. The objectives of the Federal Partners Meeting were to (1) assess current federal initiatives, resources, and potential partnerships relevant to the topic area; (2) discuss federal agency research needs, opportunities, and resources; (3) highlight prioritized panel recommendations and cross-cutting themes; (4) identify activities to address the research gaps; and (5) identify next steps for implementing recommendations and potential collaborations across agencies to set the stage for future activities. Representatives from the NICHD and NINDS led the discussion of federal agency research needs and opportunities, panel recommendations, and next steps for the field.

## 1. Summary of Discussion of Prioritized P2P Workshop Panel Recommendations Related to Key Questions

### 1a. Prioritized Recommendations Related to Key Questions

#### *Designing larger, longer-term studies and developing evidence to inform guidelines*

Related to Key Questions #1 and 4, the panel recommended conducting longitudinal studies, assessing longer-term interventions and/or longer maintenance periods following interventions, and designing larger studies with more diverse, multisite enrollment. They also recommended developing physical activity guidelines specific to wheelchair users with evidence from randomized controlled trials (RCTs) and longitudinal studies.

The Federal Partners agreed with the importance of designing larger, longer-term studies to build the evidence base. Challenges such as the diversity of wheeled mobility device users and 5-year time limits for many federal grants were discussed. Federal Partners discussed steps for supporting larger, longer-term studies to build the evidence base that can inform future guidelines including:

- Developing research tools such as activity monitors.
- Setting common definitions and recommended outcomes.
- Establishing common data elements (CDEs).

#### *Research tools*

Related to Key Question #4, the panel recommended adapting/developing consumer grade devices that can reliably capture physical activity for users of wheeled mobility devices, especially with regard to capturing the duration and intensity of physical activity. Federal Partners agreed that monitoring activity for users of wheeled mobility devices is not straightforward since much of the physical activity that individuals engage in may be outside of the scope of controlled trials or observed studies. The CDC cautioned that using activity trackers for routine physical activity monitoring has privacy concerns. Federal Partners agreed that to support longer-term studies there is a need for validated tools to monitor physical activity in people who use wheeled mobility devices that:

- Apply across conditions, the lifespan, and various types of wheeled mobility devices.
- Are independent of activity/intervention.
- May be used in the community or in a physical activity facility.

Technological advances and rapidly changing tools challenge the collection and analysis of long-term data. In addition to establishing accuracy, validated tools must take into account usability—commercial products with known popularity should be considered. Activity trackers, such as wearables, may more accurately demonstrate individual change over time, while comparisons across individuals are likely flawed due to individual variation. Additionally, analyzing data across different types of activity monitors has not been reliable to date.

### *Common data elements*

Related to Key Question #4, the panel recommended developing valid and reliable measures and employing CDEs across studies of physical activity for users of wheeled mobility devices. Federal Partners acknowledged that research studies often fail to capture wheelchair use and the need for a clearer understanding of whether participants are truly active wheelchair users (versus being passively transported) and the type and extent of wheelchair use. Federal Partners agreed there is a need for consensus on how to identify, define, and classify wheelchair use and users (i.e., powered versus manual or part-time versus full-time use) since the population is so broad and diverse. They were interested in reaching consensus on variables to recommend to researchers and CDEs. Federal Partners acknowledged that some view burden of disease measures and disability adjusted life years as potentially devaluing the lives, expectations, and experiences of people with disabilities.

### *Including wheelchair users in all phases of the research design and implementation process*

Related to Key Question #4, the panel recommended including key stakeholders (e.g., users of wheeled mobility devices) in all phases of the research design and implementation process. Federal Partners agreed that in order to develop sustainable interventions that positively impact users of wheeled mobility devices, they must be included in all phases of the process, including intervention design and selection of outcomes. Discussion included sharing internal processes at various federal agencies that could support this recommendation.

### *Representative samples and inclusion across the lifespan*

Related to Key Question #3, the panel recommended including samples that capture the full spectrum of users of wheeled mobility devices, including those with the highest-level of illness or injuries and conducting studies that ensure inclusion across the lifespan. The systematic evidence review revealed that most studies included small, homogenous samples (i.e., studies of CP included younger, higher-functioning participants). Federal Partners agreed with the importance of expanding studies to be more representative of the population on the basis of gender, age, ethnicity, level of disability, and comorbid conditions (i.e., intellectual and physical disability).

### *Assistive equipment and technology*

Related to Key Question #2, the panel recommended assessing the importance of equipment and technology, including muscle stimulation therapies. Similar to research tools, technological advances for assistive equipment challenge the collection and analysis of long-term data and access may be limited in real-world environments. Federal Partners presented substantial work in this area, shared lessons learned, and discussed next steps including supporting ongoing access to equipment and technology to promote longer-term studies and encourage sustainability.

### *Health literacy*

Related to Key Question #2, the panel recommended examining the role of health literacy in studies of intervention effectiveness. Federal Partners agreed that efforts related to health

literacy may enhance compliance with physical activity interventions allowing for a more accurate assessment of effectiveness.

*Adverse events*

Related to Key Question #2, the panel recommended compiling more comprehensive information on adverse events (AEs) and applying validated definitions to allow for data harmonization across studies. Federal Partners discussed that, although investigators monitor and report risks and AEs as a part of the Institutional Review Board (IRB) protocol, this information is rarely included in publications. It was agreed that this information is critical for all human subjects research.

*Tele-studies*

Related to Key Question #3, the panel recommended developing tele-studies to ensure greater access to the full spectrum of users of wheeled mobility devices. The Federal Partners agreed that progress in this area excelled due to COVID-19 and trends are expected to continue.

**1b. Specific Areas of Research Focus Related to Prioritized Key Questions**

An analysis conducted by ODP staff of the federal portfolio identified 75 projects initiated between 2016 and 2020 related to physical activity and in a population expected to include users of wheeled mobility devices (see Appendix C).

Agency/Organization	Total Projects per Agency/Organization
National Institutes of Health (NIH)	30
Congressional Directed Medical Research Programs (CDMRP)	15
National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR)	10
Centers for Disease Control and Prevention (CDC)	9
U.S. Department of Veterans Affairs (VA)	5
Agency of Healthcare Research and Quality (AHRQ)	4
Patient-Centered Outcomes Research Institute (PCORI)	2
<b>Total</b>	<b>75</b>

*Developing evidence to inform guidelines*

The Portfolio Review and Federal Partner presentations demonstrated efforts to strengthen the evidence base to inform future guidelines. For example:

- The NIH portfolio was largely investigator-initiated research projects (71%). Ten percent of the portfolio was Small Business Innovation Research and Small Business Technology Transfer (SBIR-STTR) demonstrating the scope of product development in this area. Over half of the grants (56.7%) were awarded through NICHD. Although NINDS awarded 20% of the grants, the total dollar amount awarded was comparable to that awarded by NICHD.

- The Congressional Directed Medical Research Programs' (CDMRP's) 15 projects included mostly clinical trials such as those within the [Spinal Cord Injury Research Program](#) (SCIRP) that examine the impacts of physical activity for individuals with SCI and projects within the [Neurotoxin Exposure Treatment Parkinson's](#) program, which examine biological mechanisms of impact from exercise and other lifestyle modifications on neurodegeneration in Parkinson's disease.
- The National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) has a portfolio of studies testing the efficacy of physical activity interventions for users of wheeled mobility devices such as those funded through the [Rehabilitation Engineering Research Centers Programs](#).

#### *Designing larger, longer-term studies*

- Many federal representatives stated that longitudinal studies are not within their agency's scope/mission since the studies funded by their agency are limited to 5-year periods of performance.
- The Veterans Affairs (VA) ensures Veterans in wheelchairs are connected to the VA's physical activity programs. For example, the VA connects Veterans to programs that promote physical activities such as [MOVE!](#) and the [National Veterans Wheelchair Games](#).
- The VA is able to conduct long-term retrospective studies by querying the electronic health record in standardized ways for specific groups such as the system of care for individuals with SCI.

#### *Research tools*

- [Medical Rehabilitation Research Resource Network](#), funded by the NICHD, NINDS, National Institute of Biomedical Imaging and Bioengineering (NIBIB), National Institute on Deafness and Other Communication Disorders (NIDCD), National Center for Complementary and Integrative Health (NCCIH), and National Institute of Nursing Research (NINR), includes two centers that focus on the use of wearable technology and video recording to assess function and measure outcomes.
- The NIH and Federal Partners have used a shared coding infrastructure to collaborate and move tools across agencies. Some agencies are restricted to funding projects that are condition-specific (e.g., CDMRP must meet congressional intent) but the NIH Institutes, Centers, and Offices (ICs) have broader missions.
- The CDC's [National Health and Nutrition Examination Survey](#) (NHANES) makes extensive use of activity trackers.

#### *Common data elements*

- The CDC stated that while they capture state and national level disability specific health data from the [Behavioral Risk Factor Surveillance System](#) (BRFSS) that shows 13.7% of adults have serious difficulty walking or climbing stairs, the data does not capture how many adults are using a wheeled mobility device.

- The CDC, through multiple projects, is involved with considering how to better define disability and develop indicators that can be utilized in response surveys.
- NINDS, with additional support from NICHD NCMRR, is leading the development of CDEs for rehabilitation research that include domains such as assessment and outcomes that apply to physical activity.
- Federal Partners such as the CDMRP and VA encourage applicants to use [NIH CDEs](#).

*Including wheelchair users in all phases of the research design and implementation process*

- CDMRP involves individuals with lived experience in:
  - Vision setting meetings to set the annual investment strategy
  - Pre-application screening to provide input for which proposals to invite for full application submission
  - Peer review with full voting rights along with other experts
  - Programmatic review to provide recommendations on which applications to fund.
- CDMRP's SCIRP requires the involvement of SCI Lived Experience Consultants throughout the planning and implementation of translational and clinical research projects.
- NIDILRR collects information on disability status for members of the investigative teams and includes qualified investigators with disabilities on review panels.
- AHRQ's [Patient-Centered Outcomes Research Dissemination and Implementation Initiative](#) promotes meaningful engagement in implementation design and implementation science.
- The CDC, through the Association of State and Territorial Health Officials (ASTHO) and the National Association of County and City Health Officials (NACCHO), embeds Disability Specialists in state health departments to inform the response effort.
- The VA's *Strengthening Excellence in Research through Veteran Engagement* is a toolkit that supports investigators in efforts to include Veterans and other stakeholders in the development, implementation, and dissemination of research studies.
- [NINDS' OPEN](#) (Office of Programs to Enhance Neuroscience Workforce Diversity) helps to include individuals with lived experience by facilitating connections between investigators with disabilities.
- NCCIH's [Biomedical Workforce Diversity Programs and Health Disparities Research](#) enhances workforce diversity through its training and career development programs.

*Representative samples and inclusion across the lifespan*

- CDMRP requires that applicants describe their strategy for including women and minorities and report the composition of the proposed study population, including sex, gender, and ethnicity.
- AHRQ's *Special Emphasis Notice (SEN): AHRQ Announces Interest in Health Services Research to Advance Health Equity* (NOT-HS-21-014) encourages applications that develop, test, and implement novel and innovative evidence-based interventions to advance equity, and thereby promote representative samples.



- CDC's *Chronic Disease Prevention Physical Activity* programs include several programs focused on increasing access including the [Racial and Ethnic Approaches to Community Health \(REACH\)](#) program that is assessing culturally-tailored interventions to address preventable risk behaviors such as physical inactivity.

#### *Assistive equipment and technology*

- NIDILRR's portfolio includes studies examining the use of: (1) active video games for youth with physical disabilities; (2) accelerometers to identify time spent in moderate to vigorous physical activities; and (3) e-health interventions to promote healthy behaviors among parents and children with physical disabilities.
- CDMRP's SCIRP includes a study of the perceived benefits of robotic exoskeletons (W81XWH-17-1-0157) and a study assessing the use of digital health technology (commercial activity trackers) for capturing changes in fitness and function for individuals with Parkinson's disease (W81XWH-20-1-0231). Many of CDMRP's studies pair physical activity with another intervention (stimulation or virtual reality device).
- The VA's [Center for Functional Electrical Stimulation](#) (FES) supports studies examining the impact of FES-assisted exercise on individuals with SCI.
- The VA's [Center for Wheelchairs and Assistive Robotic Engineering](#) supports research on smart device applications, assistive robotics and intelligent systems, human machine interfaces, and advanced wheelchair design, including customizing wheelchairs for specific sports activities.
- The VA's *Field-Based Assessment of Energy Expenditure in SCI* (5I01RX000971-03) is capturing energy expenditure using commercial sensors that attach to wheelchairs and users' wrists.
- The National Heart, Lung, and Blood Institute's (NHLBI) *Hybrid-FES Exercise to Prevent Cardiopulmonary Declines in Acute High Level SCI* (2R01HL117037-06A1) examines FES row training coupled with volitional arm and electrically controlled leg exercise.
- NICHD's *Pediatric Gait Rehabilitation Via Wearable Robotic Assistance* (1R03HD094583-01) examined walking with an assistive exoskeleton for children with CP.
- NICHD's *FitMi Plus: Smart Functional Modules for Practicing Activities of Daily Living after Stroke* (1R44HD097803-01) examines a system for motivating home therapeutic exercise.

#### *Health literacy*

- The CDC tailors informational materials to be more responsive to individuals in different disability groups.
- AHRQ's focus on patient-centered care and health equity supports work in health literacy.

#### *Adverse events*

- No current efforts were shared related to efforts encouraging the reporting of AEs.

### *Tele-studies*

- CDMRP indicated that most studies that were not originally designed as tele-studies were able to successfully move to a telehealth approach due to COVID-19 and provide remote intervention and data collection. One advantage to tele-studies is that the ability to screen, enroll, and assess remotely has expanded data catchment areas.
- Since many Veterans are located in rural areas, the VA has an extensive telehealth system for patient care delivery. One of the highlighted tele-studies included a home-based exercise program for individuals with Parkinson’s disease.
- NINR’s *Telehealth High Intensity Interval Exercise and Cardiometabolic Health in SCI* (1R21NR019309-01) assesses changes in cardiometabolic health and physical function from a home-based, telehealth, high intensity interval, arm crank exercise training program in individuals with SCI.

## **1c. The Federal Partners Identified the Following Opportunities, Resources, and Action Items**

### *Designing larger, longer-term studies and developing evidence to inform guidelines*

- Acknowledging that many federal agencies do not have the ability to fund longitudinal studies, Federal Partners explored the possibilities of encouraging disability-related communities such as the National Paralysis Resource Center to engage disability communities in longer-term data collection—recognizing that such communities would need substantial technical assistance to build capacity to collect usable data.
- NIH’s [Molecular Transducers of Physical Activity Consortium](#) (MoTrPAC) can support studies on how exercise improves health.
- The VA Cooperative Studies Program funds larger and longer-term multisite clinical trials, including the *Powered Exoskeletons in Persons with SCI* (PEPSCI) study (NCT02658656), examining the safety and efficacy of powered exoskeletons for home and community use.
- The VA’s [Health Economics Resource Center](#) supports the development of cost-effectiveness analyses.
- AHRQ may address research gaps related to physical activity in users of wheeled mobility devices through potential future systematic reviews of future longitudinal observational studies and RCTs.
- CDC partners in the development of [Physical Activity Recommendations and Guidance](#).
- The VA/Department of Defense (DoD) [Evidence-Based Practice Guideline Work Group](#) maintains and updates clinical practice guidelines.

### *Research tools*

- NICHD may have an opportunity to include language related to creating measures and validating tools in the *Notice of Special Interest (NOSI): Diet, Physical Activity, Sedentary Behavior and Sleep Assessment*.
- NIH and the National Science Foundation (NSF) may add target areas to the joint initiative, *Smart and Connected Health (SCH): Connecting Data, People and Systems* (NSF

18-541) and develop a communications strategy to reach out to communities to promote new applications.

- NIH, NICHD, and NINDS may consider competitive revisions to promote the creation of measures and the validation of tools.
- The VA can partner to jointly fund projects with other federal agencies. Although VA-funded research must be focused on Veteran needs, many VA investigators have joint academic appointments. These researchers can work directly with other federal agencies on their university time and focus on non-Veteran populations.
- NIH's [Advanced Research Projects Agency for Health](#) (ARPA-H), if established, may be a mechanism for tool development.

#### *Common data elements*

- NIH may convene a meeting to define users of wheeled mobility devices and standardized measures that may be referenced in future program applications to guide the field.
- NIH, CDMRP, and the VA may convene to discuss priorities for SCI.
- NIDILRR emphasized the need for a broad array of outcomes including individual-level and environment-level outcomes including physical, social, and economic accessibility to physical activity interventions. Additionally, psychological outcomes and distal outcomes, such as employment and community living, are needed to capture the broader human benefits of physical activity. [Model SCI systems](#) may have some standard measures to share.
- The VA has a whole health and wellness approach to Veteran care supported by an electronic health record from which standard measures could be extracted.
- AHRQ's [Outcomes Measures Harmonization](#) projects may be of value in collaborative efforts to develop CDEs.

#### *Including wheelchair users in all phases of the research design and implementation process*

- Federal Partners agreed that elements of CDMRP's and NIDILRR's processes that include individuals with lived experience in all phases of the research design can serve as a model for other agencies.

#### *Representative samples and inclusion across the lifespan*

- NIDILRR recommends examining the utility of cross-disability technologies, such as screen readers, to increase access to physical activity interventions.
- NIDILRR and NIH recommend that special consideration be given to the pediatric population such as encouraging that accelerometers and wearable technology are calibrated to different wheel sizes.
- AHRQ will consider how to increase the focus within the health equity portfolio on physical activity and users of wheeled mobility devices.
- NICHD recommends considering the special needs of individuals with intellectual and physical disabilities to ensure their inclusion in samples.

### *Equipment and technology*

- Federal Partners agreed that continued funding of device development (both exercise equipment and activity trackers) along with apps is a better investment than app development alone, as apps tend to become obsolete.
- Federal Partners agreed that device development and research studies should be conducted in parallel and inform each other.

### *Health literacy*

- CDMRP will consider how to leverage ongoing health literacy efforts to help with consumer engagement and ensure funded research is of highest impact to people with lived experience.
- AHRQ is interested in partnering on work in this area.
- Federal Partners may consider connecting to organizations such as Paralyzed Veterans of America, Unite to Fight Paralysis, and North American Spinal Cord Injury Consortium that also engage in health literacy.

### *Adverse events*

- NIH can inform grantees of NIH policies that research participant safety and safety monitoring are critical to the science, and that the NIH would like to see AEs reported in the literature.
- NIH can consider unique AEs that are likely associated with specific populations and interventions and create a list that may be used to initiate discussions with grantees to capture that data.
- AHRQ is interested in partnering on work in this area, specifically incorporating common and patient-oriented AEs in comparative effectiveness research.

## **2. Summary of Discussion of P2P Workshop Panel Cross-Cutting Themes**

### **2a. Brief Description of Cross-Cutting Themes**

Federal Partners discussed the panel's three cross-cutting themes and agreed that the themes are critical to advancing the evidence-based interventions for physical activity and users of wheeled mobility devices.

#### *What Matters Most*

Panelists encouraged researchers to consider what matters most to users of wheeled mobility devices as well as the perspectives of other stakeholders including spouses, children, other family members, caregivers, and healthcare providers. Interventions demonstrating outcomes that are most relevant to individuals with lived experience are more likely to be adopted and sustainable.

### *Translation of Research into Practice*

Currently, evidence-based physical activity interventions for users of wheeled mobility devices are not readily scaled-up in community settings. Panelists recommended that researchers consider real-world issues such as insurance coverage, reimbursement challenges, and the availability of assistive equipment outside the research context as well as the foundational concepts of implementation science at the earliest stages of research planning.

### *Research Infrastructure*

The panel called for a more robust national research infrastructure to support studies of physical activity for users of wheeled mobility devices. Recommendations include standardized outcome measures to allow for harmonization of data across studies and the development of a national data repository.

## **2b. Specific Areas of Research Focus Related to Cross-Cutting Themes**

### *What Matters Most*

- AHRQ's grant, *Addressing the Needs of Individuals Early After Stroke: An Adaptation of the 14-Weeks to a Healthier You Program* (F32HS024366) gains a patient-centered understanding of facilitators and barriers to physical activity and tailors interventions to individuals' needs.
- AHRQ's grant, *Physical Therapy Delivery Models for Long-Term Parkinson's Disease Management* (1F32HS025077-01) collects patient and provider perspectives on barriers and facilitators to the delivery of evidence-based physical therapy for individuals with long-term Parkinson's disease.

### *Translation of Research into Practice*

- *NOSI: Developing and Testing Multilevel Physical Activity Interventions to Improve Health and Well-Being* (NOT-OD-21-087), issued by ODP with several ICs signing on, encourages applications of translational research aimed at testing scalable and sustainable physical activity interventions.
- AHRQ's grant, *Preventing Hospital-Acquired Disability: An Intervention to Improve Older Adult Patient Ambulation* (1R01HS026733-01A1) tests the effectiveness of a physical activity intervention for older adults upon discharge from the hospital and the translation of the intervention in changes in nurse behaviors and unit culture.
- AHRQ's grant, *Leveraging Physical Therapy to Improve Physical Activity in Older Adults with Chronic MSK Conditions* (1K01HS026518-01) assesses patient and clinician perspectives on barriers and facilitators to implementing a physical activity intervention for older adults with chronic musculoskeletal (MSK) conditions.
- The CDC supports the [National Center on Health, Physical Activity and Disability](#) (NCHPAD) and [Special Olympics](#) to promote best practices and improve access to physical activity interventions.
- The CDC also supports [State Disability and Health Programs](#) to increase knowledge and awareness of effective programs, policies, systems, and environmental changes for

people with mobility limitations. Also through the [Reaching People with Disabilities through Health Communities](#) project, the CDC promotes policy, systems, and environmental changes (such as making walking routes accessible and adopting inclusive physical activity policies in schools) that allow individuals with disability to engage in health promotion projects within their communities.

- The VA's [Quality Enhancement Research Initiative](#) (QUERI) includes a national network of 200+ investigators who apply a three-fold strategic methodology focused on implementation, evaluation, dissemination, and sustainability.

#### *Research Infrastructure*

- NICHD NCMRR, with support from the VA, DoD, and other Federal Partners, funded the development of the [Limb Loss and Preservation Registry](#).

## **2c. The Federal Partners Identified the Following Opportunities, Resources, and Action Items**

#### *What Matters Most*

- NIH may convene a meeting to re-affirm the values and goals for research in this area, such as including individuals with lived experiences in all aspects of the planning and implementation process and engaging them in defining outcomes that capture what matters most to users of wheeled mobility devices.
- Federal Partners may encourage researchers to focus on outcomes that matter most to users of wheeled mobility devices by adopting some CDMRP processes such as embedding focus areas in program announcements and engaging in strategic selection based on both technical merit and program priorities.
- NIH may also consider adapting NIDILRR's process of including language in the NOSI to encourage work in the area as well as scoring criteria to guide the review of applications.
- AHRQ is interested in collaborating on the development of common and patient-centered outcomes.
- CDMRP stated that in their next vision setting meeting for SCIRP, they will consider including interventions' effects on families and caregivers.
- The VA has two programs that could support the involvement of caregivers—[The Elizabeth Dole Center of Excellence for Veteran and Caregiver Research](#) and [VA Caregiver Support Program](#).

#### *Translation of Research into Practice*

- AHRQ may address research gaps related to physical activity in users of wheeled mobility devices through the [Patient-Centered Outcomes Research Dissemination and Implementation Initiative](#) and the use of implementation methodologies to scale-up, spread, and sustain interventions.
- AHRQ portfolio could support research examining barriers to accessibility of medical equipment or other access barriers for the uptake of physical activity interventions.

### *Research Infrastructure*

- Federal Partners agreed that defining users of wheeled mobility devices and developing CDEs is the first step towards developing research infrastructure (see above).
- Federal Partners expressed interest in identifying an existing data repository that may promote longitudinal studies.
- AHRQ has a strong focus on registries and would like to collaborate on any efforts related to registries in this area.
- AHRQ's [Registry of Patient Registries](#) may be of value in the development and dissemination of a national data repository.

### **3. Next Steps and Concluding Remarks**

Federal Partners were asked to disseminate the systematic evidence review and P2P workshop panel report publications to their networks and audiences. Federal Partners agreed to look for opportunities to share the findings with their networks of investigators and other stakeholders.

- NIDILRR expressed interest in a joint State of the Science meeting to share findings with users of wheeled mobility devices and related organizations.
- NIDILRR discussed disseminating the panel recommendations to the [SCI Model Systems](#) (i.e., spinal cord (SCIMS), traumatic brain injury (TBIMS), etc.) to encourage the development of CDEs and evidence to inform guidelines.
- NIDILRR and NINDS suggested disseminating the recommendations to policy groups to inform policy updates or changes. For example, the Architectural Access Board was instrumental in increasing accessibility to pool lifts in hotels and is currently working on increasing access to assistive cardio equipment for users of wheeled mobility devices.

## References

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APPENDIX A

NATIONAL INSTITUTES OF HEALTH PATHWAYS TO PREVENTION (P2P) PROGRAM:  
CAN PHYSICAL ACTIVITY IMPROVE THE HEALTH OF WHEELCHAIR USERS?  
FEDERAL PARTNERS MEETING  
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## APPENDIX B

### NATIONAL INSTITUTES OF HEALTH PATHWAYS TO PREVENTION (P2P) PROGRAM: CAN PHYSICAL ACTIVITY IMPROVE THE HEALTH OF WHEELCHAIR USERS? WORKSHOP PANEL RECOMMENDATIONS

#### Recommendations Related to Key Question #1:

1. Include users of wheeled mobility devices in population-based, prospective observational studies with measures of physical activity and health outcomes.
2. Conduct longitudinal observational studies examining the risk of developing chronic conditions (e.g., cardiovascular disease, diabetes, and obesity) over time among people currently using or who may use wheeled mobility devices in the future.
3. Incorporate symptom burden (e.g., pain and fatigue), functional decline, and health-related quality of life measures in longitudinal observational studies. Quantify burden of disease measures (e.g., healthy life expectancy, years of life lost, years lived with disability, disability adjusted life years) as part of the health outcomes assessed.
4. With evidence from RCTs and longitudinal observational studies, develop evidence-informed physical activity guidelines specific to people currently using or who may use wheeled mobility devices in the future.

#### Recommendations Related to Key Question #2:

1. Quantify the benefits and harms of physical activity on long-term health outcomes among people currently using or who may use wheeled mobility devices in the future.
2. Assess the importance of equipment and technology, including muscle stimulation therapies.
3. Diversify outcomes to assess how factors such as cognition, mental health, and negative experiences (e.g., injury, perceived burden) are linked with study participation.
4. Examine the role of health literacy for the effectiveness of interventions.
5. Include individual and family/caregiver-level outcomes.
6. Compile more comprehensive information on AEs, applying validated definitions that allow for data harmonization across studies. Information on AEs should include type, severity, timing, duration, and assessment of causality.

#### Recommendations Related to Key Question #3:

1. Consider the role of age, sex, gender, and intersectionality in developing a research agenda on the benefits and harms of physical activity interventions for people currently using or who may use wheeled mobility devices in the future.
2. Use community-based participatory research approaches to engage a more representative population to produce generalizable research findings that can lead to meaningful health benefits.
3. Promote studies that span all levels of functional status and disease severity. Studies that focus on Gross Motor Function Classification System (GMFCS IV-V) populations and patients with more severe MS, CP, and SCI are especially needed.

4. Conduct studies to assess the impact of physical activity on “universal health outcomes” including symptom burden (e.g., pain and fatigue), functional decline, and health-related quality of life in people currently using or who may use wheeled mobility devices in the future—overall and according to patient-level factors.
5. Include samples that capture the full spectrum of users of wheeled mobility devices, including those with the highest-level injuries.
6. Consider sedentary behavior, which may modify the impact of physical activity, such that wheelchair users with co-occurring high physical activity and high sedentary behavior may be at greater risk for adverse health outcomes than those with high physical activity and low sedentary behavior.
7. Conduct studies that ensure inclusion across the lifespan.
8. Develop tele-studies to ensure greater access to the full spectrum of users of wheeled mobility devices.

**Recommendations Related to Key Question #4:**

1. Develop valid and reliable measures to assess physical activity among diverse samples of users of wheeled mobility devices.
2. Include key stakeholders (e.g., wheelchair users) in all phases of the research design and implementation process.
3. Promote study designs that evaluate dosing and intensity of physical activity for people currently using or who may use wheeled mobility devices in the future.
4. Employ CDEs across studies of physical activity for users of wheeled mobility devices.
5. Focus on adapting/developing consumer grade devices that can reliably capture physical activity for users of wheeled mobility devices, especially with regard to capturing the duration and intensity of physical activity.
6. Assess longer interventions and/or longer maintenance periods following interventions. Scrutinize whether an inactive control group is ethical. Consider alternative control conditions to provide benefit to enrolled participants.
7. Assess mechanisms of effect (e.g., fitness, depression, sleep, pain, fatigue, blood pressure).
8. Conduct clinical trials based on impairments and functional deficits rather than just underlying diagnosis and pathology.
9. Identify and measure mediators, moderators, and process measures, as well as behavioral change techniques in interventions and incorporate behavioral change theory into interventions.
10. Consider rigorous study designs to assess adaptive interventions (e.g., Self-Management Assistance Through Technology [SMART]).
11. Lengthen the typical intervention period of 6–12 weeks as indicated by the systematic review and track outcomes beyond the immediate intervention period in order to capture variability and assess longer-term health outcomes.

12. Design larger studies with more diverse, multisite enrollment to enhance generalizability of the research.
13. Use cost-effectiveness analysis to support policy change relevant to evidence on physical activity and health for wheelchair users.

**APPENDIX C**

**FEDERAL PARTNER CURRENT RELEVANT ACTIVITIES 2016–2020**

Agency		Type of Activity	Activity Name (Grant, Contract, Intramural Research Project, Funding Opportunity Announcement, Workshop, Community Initiative, or Other)
AHRQ		Grant	Physical Therapy Delivery Models for Long-Term Parkinson’s Disease Management
AHRQ		Grant	Addressing the Needs of Individuals Early After Stroke: An Adaptation of the 14-Weeks to a Healthier You Program
AHRQ		Grant	Leveraging Physical Therapy to Improve Physical Activity in Older Adults with Chronic Musculoskeletal Conditions
AHRQ		Grant	Preventing Hospital-Acquired Disability: An Intervention to Improve Older Adult Patient Ambulation
DOD-CDMRP		Grant	W81XWH-17-1-0448: Evaluating the Metabolic Changes Associated with Exercise in MS
DOD-CDMRP		Grant	W81XWH-18-1-0530: Improving SCI Rehabilitation Interventions by Retraining the Brain
DOD-CDMRP		Grant	W81XWH-18-1-0796: Mechanisms and Efficacy of High-Intensity Variable Training in Patients with Incomplete SCI
DOD-CDMRP		Grant	W81XWH-19-1-0330: Impact and Interplay of Corticosteroid Regimen and Exercise Training on Duchenne Muscular Dystrophy (DMD) Muscle Function
DOD-CDMRP		Grant	W81XWH-19-1-0734: Targeting Improvements in Bowel Function and Quality of Life Using Epidural Stimulation and Training After Severe SCI
DOD-CDMRP		Grant	W81XWH-19-1-0810: Exercise and Plasticity in Parkinson’s Disease: Functional and Structural Evidence in the Cortex and the Spinal Cord
DOD-CDMRP		Grant	W81XWH-19-1-0812: Effects Of Exercise On Glymphatic Functioning And Neurobehavioral Correlates In Parkinson's Disease
DOD-CDMRP		Grant	W81XWH-18-1-0665: Investigating Exercise-Induced Neuroplasticity and Its Mechanisms in Parkinson's Disease: Targeting Executive Function and Brain Circuitry
DOD-CDMRP		Grant	W81XWH-19-1-0443: The Role of Astrocytes and Microglia in Exercise-Induced Neuroplasticity in Parkinson's Disease
DOD-CDMRP		Grant	W81XWH-20-1-0231: Accelerating Physical Therapy Exercise Monitoring: Facilitators, Fidelity, and Fitness
DOD-CDMRP		Grant	W81XWH-17-1-0340: Effect of a Novel Intervention Using Daily Intermittent Hypoxia and High-Intensity Training on Upper-Limb Function in Individuals with SCI



Agency		Type of Activity	Activity Name (Grant, Contract, Intramural Research Project, Funding Opportunity Announcement, Workshop, Community Initiative, or Other)
DOD-CDMRP		Grant	W81XWH-17-1-0157: Evaluating the Utilization and Efficiency of Wearable Exoskeletons for SCI Rehabilitation
DOD-CDMRP		Grant	W81XWH-18-1-0718: Acute Intermittent Hypoxia and Respiratory Strength Training to Improve Breathing Function After SCI
DOD-CDMRP		Grant	W81XWH-20-1-0845: Epidural Stimulation and Resistance Training for Overground Locomotion After SCI
DOD-CDMRP		Grant	W81XWH-20-1-0775: A Multisite Randomized Clinical Trial to Examine the Efficacy and Mechanisms of Immersive Virtual Walking Treatment for Neuropathic Pain in SCI
NIDILRR		Grant	90DPGE0005: Scale-Up Of An Innovative, Evidence-Based Movement-2-Music (M2M) Intervention For Adults With Physical/Mobility Disability
NIDILRR		Grant	90IFST0001: The Disability, Rehabilitation, Engineering Access For Minorities (Dream) Project
NIDILRR		Grant	90REGE0002: Rehabilitation Engineering Research Center on Exercise and Recreational Technologies for People with Disabilities
NIDILRR		Grant	90DP0056: Self-Management Assistance Through Technology (SMART) - Virtual Coaches for Wheelchair Users
NIDILRR		Grant	90IFRE0037: Scale Up Trial of Project WOWii to Increase Exercise Among People with SCI
NIDILRR		Grant	90REGE0011: Rehabilitation Engineering Research Center on ICT Access for Mobile Rehabilitation (mRehab)
NIDILRR		Grant	90IFRE0022: Building an Evidence-Base for Weight Loss Strategies Among Those with SCI
NIDILRR		Grant	90SI5018: Southern California SCI Model System at Rancho Los Amigos National Rehabilitation Center
NIDILRR		Grant	90DP0074: A Lifestyle Intervention Targeting Enhanced Health and Function for Persons with Chronic SCI in Caregiver/Care-Receiver Relationships: Effects of Caregiver Co-Treatment
NIDILRR		Grant	90IFDV0018: Harnessing Social Networks to Personalize Sensor-Driven, Just-In-Time Physical Activity Interventions for Individuals With SCI
NIH	CLC	Intramural Research Project	1ZIACL060076-08: Physical, Functional and Neurological Effects of Exercise in Children with CP

Agency		Type of Activity	Activity Name (Grant, Contract, Intramural Research Project, Funding Opportunity Announcement, Workshop, Community Initiative, or Other)
NIH	NHLBI	Grant	2R01HL117037-06A1: Hybrid-FES Exercise to Prevent Cardiopulmonary Declines in Acute High-level SCI
NIH	NIA	Grant	1R43AG064990-01A1: MiGo-Wheels: A comprehensive feedback system to help wheelchair users maintain a healthy lifestyle
NIH	NICHD	Grant	1F31HD097903-01A1: Restless legs syndrome and physical activity in adults with MS
NIH	NICHD	Grant	1F32HD101214-01: Development of a wheelchair exercise training program for persons with MS using a community-engaged research approach
NIH	NICHD	Grant	1K23HD101667-01: Aerobic exercise to improve mobility in MS: optimizing design and execution for a full-scale multimodal remyelination clinical trial
NIH	NICHD	Grant	1R01HD083384-01A1: Daily and Weekly Rehabilitation Delivery for young children with CP (DRIVE Study)
NIH	NICHD	Grant	1R01HD085930-01: Ischemic Conditioning as a Neurorecovery Agent for Stroke
NIH	NICHD	Grant	1R01HD090126-01A1: Effect of vibration on muscle properties, physical activity and balance in children with CP
NIH	NICHD	Grant	1R01HD091155-01A1: Treadmill Walking Exercise Training Effects on Cognition and Brain Function in Multiple Sclerosis: A Systematically-Developed Randomized Controlled Trial
NIH	NICHD	Grant	1R01HD093724-01: Multimodality Intervention to Improve Function and Metabolism in SCI
NIH	NICHD	Grant	1R01HD097407-01A1: An exercise intervention to Reduce Neuropathic Pain and Brain Inflammation after SCI
NIH	NICHD	Grant	1R01HD098270-01: Short-Burst Interval Treadmill Training to Improve Community Walking Activity and Mobility in CP
NIH	NICHD	Grant	1R01HD100383-01: Mobility in Daily Life and Falls in Parkinson's Disease: Potential for Rehabilitation
NIH	NICHD	Grant	1R01HD100544-01: Priming with High-Frequency Trans-spinal Stimulation to Augment Locomotor Training Benefits in SCI
NIH	NICHD	Grant	1R01HD101900-01: Evaluation of the Efficacy of a Physical Therapy Intervention Targeting Sitting and Reaching for Young Children with CP
NIH	NICHD	Grant	1R03HD094583-01: Pediatric Gait Rehabilitation Via Wearable Robotic Assistance

Agency		Type of Activity	Activity Name (Grant, Contract, Intramural Research Project, Funding Opportunity Announcement, Workshop, Community Initiative, or Other)
NIH	NICHD	Grant	1R03HD097727-01: NEO rehab program for premature infants at risk for CP
NIH	NICHD	Grant	1R21HD087840-01A1: Post-PT Extension of In-Home Dynamic Standing Table Use in Parkinson's Disease
NIH	NICHD	Grant	1R44HD097803-01: FitMi Plus: Smart Functional Modules for Practicing Activities of Daily Living after Stroke
NIH	NIDDK	Grant	1R01DK116669-01A1: Weight management for adults with mobility related disabilities
NIH	NINDS	Grant	1R01NS100810-01A1: Closed loop control of vibration for muscle spasms after human SCI: efficacy and mechanism
NIH	NINDS	Grant	1R01NS114279-01: Characterization of Physiological Changes Induced Through MEP Conditioning in People with SCI
NIH	NINDS	Grant	1R21NS118764-01: Imaging Biomarkers of Exercise-Induced Brain Changes in Parkinson's Disease
NIH	NINDS	Grant	1R44NS110237-01: Enhancing Physical Therapy with Brain Stimulation for Treating Postural Instability
NIH	NINDS	Grant	1U01NS106655-01A1: Perinatal Arterial Stroke: A Multi-site RCT of Intensive Infant Rehabilitation (I-ACQUIRE)
NIH	NINDS	Grant	1U01NS113851-01: Study in Parkinson's Disease of Exercise Phase 3 Clinical Trial: SPARX3
NIH	NINR	Grant	1R21NR019309-01: Telehealth high intensity interval exercise and cardiometabolic health in SCI
VA		Intramural Research Project	1I01RX002967-01A2: Partnered Dance Aerobic Exercise as a neuroprotective, motor and cognitive intervention in Parkinson's disease
VA		Intramural Research Project	1I01RX002987-01A1: Long Term Aerobic Exercise to Slow Progression in Parkinson's Disease
VA		Intramural Research Project	1I01RX003055-01A1: Highly challenging balance program to reduce fall rate in Parkinson's disease
VA		Intramural Research Project	1I21RX002362-01: Telephone-linked, home-based exercise training in Parkinson's disease

Agency		Type of Activity	Activity Name (Grant, Contract, Intramural Research Project, Funding Opportunity Announcement, Workshop, Community Initiative, or Other)
VA		Intramural Research Project	1K2RX002341-01A2: Protective Step Training in People with MS