

Can Technology Improve Participation From Underserved Children and Families In Rehabilitation Research?

Samuel T. Nemanich, PhD, MSCI; Bernadette T. Gillick, PhD, MSPT, PT; Theresa Sukal-Moulton, DPT, PhD; Sheikh Iqbal Ahamed, PhD

Rigorous translational research for children with disabilities is essential for providing evidence for early detection and intervention and to continue to bridge the knowledge-practice divide.^{1,2} Moreover, incorporating key stakeholders—mainly children and families—is pivotal for conducting family-focused research that is generalizable and directly informs clinical practice. Because a large percentage of research requires in-person visits and interaction with research staff, the interruptions caused by the COVID-19 pandemic have provided an opportunity to reflect and reevaluate on how and where research can and should be conducted. As pediatric rehabilitation researchers working in a variety of geographic settings across Wisconsin and Illinois drawing upon prior literature and lessons learned from the pandemic, we propose that technology can help establish a “new normal” for conducting equitable and inclusive rehabilitation research amid a global pandemic.

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Author Affiliations: Department of Occupational Therapy, Marquette University, Milwaukee, Wisconsin (Nemanich); Department of Pediatrics, University of Wisconsin-Madison, Madison, Wis (Gillick); Department of Physical Therapy, Northwestern University, Chicago, Illinois (Sukal-Moulton); Department of Computer Science, Marquette University, Milwaukee, Wis (Ahamed).

Corresponding Author: Samuel T. Nemanich, PhD, MSCI, Assistant Professor, Department of Occupational Therapy, Marquette University, PO Box 1881, 1700 Building, Room 140, Milwaukee, WI 53201; phone 414.288.3243; email sam.nemanich@marquette.edu; ORCID ID 0000-0001-6093-7266

IN-PERSON RESEARCH LIMITATIONS

In-person research is comfortable and familiar to most researchers. Historically, however, this approach has several limitations that were further magnified during the pandemic. First, and perhaps most obvious, in-person research is not feasible when physical interaction is restricted by public health guidelines. During

research participants. Underrepresented racial and ethnic minority groups are less likely to have flexible work schedules or paid time off to participate in studies.⁴ For those with availability, travel becomes problematic if there is limited access to transportation to reach research locations. Furthermore, both time and travel are barriers for families in rural areas who do

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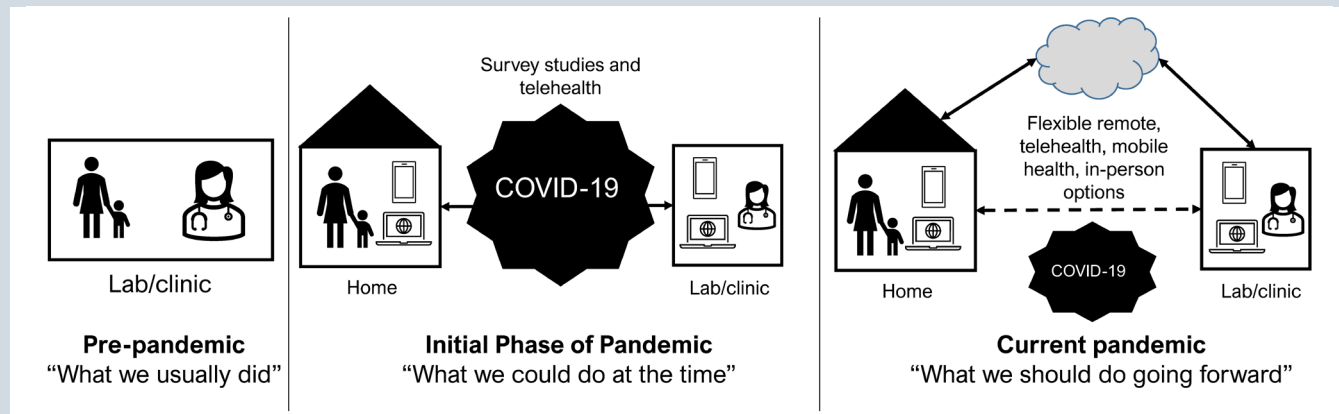
the pandemic, many learned that most daily activities and functions could be adapted to reduce in-person interaction (eg, goods and services delivery, telecommuting, virtual education). Influenced by these new options, many research participants also may expect alternative options to in-person research. Stakeholders feel that remote methods save time, effort, and money for travel costs.³ While some research protocols require specialized procedures and must be performed in-person, there are also many protocols, or portions of protocols, that could be modified to be performed remotely, such as obtaining informed consent. Such modifications do require compliant preparation with appropriate oversight and approval but can offer added benefit to prospective participants.

Before the pandemic, more common factors that limited in-person interaction included time and travel barriers. These problems are intertwined with issues of diversity and inclusion of

not live near a research site, which are typically in large exurban and urban areas. Remote research offers the benefit of eliminating time and travel barriers to reach a broader and more representative population of research participants.

There are other scientifically relevant reasons to move toward remote research methodologies. Traditional in-person research designs capture information over a relatively small window of time and do not measure day-to-day or week-to-week changes that reflect the variability and heterogeneity of behaviors that exist across different time scales and in different environments, resulting in limited generalizability of the findings.⁵ Remote research would facilitate longitudinal designs in ecologically relevant contexts that would address otherwise unanswered questions. For example, the stability and long-term effects of many physical and occupational therapy interventions are not well

Figure. Model of Past and Proposed Future Changes to Pediatric Rehabilitation Research



Before the pandemic, traditional research usually consisted of in-person visits to a laboratory or clinic. This was done to maintain control of experimental conditions and because specialized equipment or technology was present in the laboratory. During the initial phase of the pandemic, researchers were limited to performing survey studies with limited technology as most were not prepared to perform rigorous remote research. Now, moving forward with COVID still present in our daily lives, researchers should consider remote, telehealth, and in-person formats when designing future studies. With this approach, families will spend less time traveling to research facilities, and longitudinal work and follow-up work may be more feasible. Remote research is facilitated by the ubiquity of computers and mobile devices and broadband internet.

understood. Knowledge of longevity and stability of treatments would help clinicians better understand prognosis and long-term outcomes.

In-person research also captures a participant's performance and abilities in a specialized laboratory environment that may not translate to other settings or contexts. For example, in adults with stroke, prior work has shown there is a significant difference between the quantity a person moves in a clinical setting compared to a home or community setting.⁶ This study clearly outlines a need to understand phenomena—like motor skill development and recovery from injury—from a broader perspective and to consider the contextual and environmental factors that drive these differences in behaviors. Understanding how individuals behave in the home is even more important because it is where people spend more time due to adjustments made during the pandemic. Future work that can gather valid data in various environments could provide a unique window into individual behaviors in nontraditional research settings.

REMOTELY EVALUATING CHILDREN'S MOTOR DEVELOPMENT: A MODEL FOR MOVING RESEARCH OUTSIDE THE LABORATORY

For pediatric rehabilitation researchers studying children with physical disabilities, a critical area of research surrounds how motor skills

are assessed and evaluated. Healthy acquisition of motor skills is a key part of a child's overall development. Motor skills are linked to academic success, enable social development, and are predictive of overall physical health and well-being.^{7,8} Valid and reliable assessments of motor skills maximize the rigor of scientific studies and provide clinicians evidence-based evaluation tools to inform decision-making for children at risk for developmental differences. For families, being a part of the assessment process is important, with some families preferring assessments that don't require clinic visits.⁹ Thus, exploring how assessments can be performed remotely supports a family-focused, stakeholder-driven approach to research. Still, currently available motor assessments are almost always performed face-to-face, require proprietary equipment and scoring manuals, and last upwards of 1 hour to administer. Most assessments are not designed to detect subtle or mild difficulties a child may experience, nor can they track the rapid and nonlinear changes that may occur throughout development. Accurate and timely motor assessments that can be completed in the home with or without a clinician and are linked to a child's expected development could help to fill this gap. Such information also may provide reassurance to parents about how their children are functioning and if certain behaviors are typical.¹⁰ Altogether, there is an opportunity for improv-

ing how, where, and when assessments are administered.

TECHNOLOGY-FOCUSED SOLUTIONS

There is a range of potential solutions with varying degrees of technological sophistication. Focusing on solutions that involve readily available technology, such as mobile devices, allows for participation in any environment and also helps narrow the inequity gap: a large majority (76% and more) of Americans from different racial and socioeconomic groups own a smartphone.¹¹ Thus, research participation involving mobile devices does not require owning or purchasing other technology than what a participant already has. Mobile health (mHealth) solutions are advantageous because they capitalize on existing technology infrastructure (broadband and wireless internet, mobile devices, smartphones). The BabyMoves app is an example of an mHealth teleassessment solution designed to determine risk of developmental delays in newborns that is performed outside a laboratory or clinical environment.^{12,13} This solution illustrates the flexibility and power of mobile devices to communicate, collect, and transmit clinical outcome data. While common in other disciplines, mHealth solutions have yet to be thoroughly explored for pediatric rehabilitation assessment research.

Moving toward more quantitative and objective motor assessments, solutions for

portable and remote movement data collection have been explored by motor neuroscience and neurorehabilitation researchers. One solution was the Portable Motor learning laboratory (PoMLab), a freely available platform that uses software applications running on smartphone or tablet devices that implement commonly used protocols for precise study of motor learning that can be performed in any environment.¹⁴ A similar solution was proposed by Matic and Gomez-Marin, who created a customizable tablet application for measuring hand movement function.¹⁵ The application records a cursor position of the task being performed and measures spatiotemporal variables related to movement skill and performance. One benefit to these solutions is that they use common mobile devices (smartphones, iPads) and may not require additional sensors or external equipment. Furthermore, the software is freely available and could be adapted for pediatric applications. We are exploring development of an mHealth application to collect pediatric motor performance data based on these existing technologies to address these research gaps.

CONCLUSIONS AND FUTURE DIRECTIONS

The Figure illustrates how a shift from in-person to remote research in the context motivated by the COVID-19 pandemic might impact research participation. During the early lockdown phase of the pandemic, research was suspended, leaving investigators with fewer options to continue their research, thus magnifying the limitations of in-person research. Recognizing these limitations, combined with the uncertainty of pandemic and future outbreaks, we propose that researchers should implement alternatives to in-person participation to accommodate participation, particularly those from underrepresented groups.

There are potential barriers to pivoting to fully remote approaches worth noting. Despite the ubiquity of smartphones and mobile devices, the requirement of owning a piece of technology to be included in a study may still pose an obstacle for some underserved families. Remote studies also may limit extended interpersonal interactions achieved with in-person studies that build rapport and trust between families and the research team. Such

interactions are critical for continued participation and engagement in the research process. Finally, concerns of privacy and data security deserve careful consideration when health and identifiable data are transmitted remotely and stored on portable devices. Good practices for data security and confidentiality should be established before pursuing wide-scale remote research studies. Considering these potential limitations, traditional in-person research has its merits and should not be discontinued, but rather it should be complemented by including remote options supported by the technological advances capable of directly communicating with and collecting objective information from individuals within their natural environments.

Equitable recruitment and enrollment will continue to be a challenge. Given the disparities in research participation among underrepresented racial, ethnic, and socioeconomic groups, there are key questions when designing studies that deserve honest consideration: *Who will benefit from my research? How can I make my procedures more accommodating to families? Can I expand my study to a larger part of the population?* Improving diversity in research requires intention on behalf of the researcher to consider these questions and to actively work within their own communities to include community members who represent diverse groups in the research process. Overall, the effects of the pandemic require that we strive for a “new normal” to improve how we conduct research and interact with families. If properly implemented, research outcomes will be more generalizable and will help bridge the research-practice divide.

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