

## Engaging Individuals with Neurological Conditions and Caregivers in Rural Communities in a Health Research Team

Kathleen M. Sutton, PT, DPT, MPH, CPH,<sup>1</sup> Patrick H. Kitzman, PT, PhD,<sup>2</sup> Elizabeth G. Hunter, PhD, OTR/L,<sup>3</sup> Keisha Hudson,<sup>4</sup> Carolyn Wallace,<sup>5</sup> Violet Sylvia, PhD,<sup>6</sup> Julia Brock, MA<sup>2</sup>

(1) Rehabilitation Sciences, University of Kentucky; (2) Physical Therapy, University of Kentucky; (3) Graduate Center for Gerontology, University of Kentucky; (4) Center of Excellence in Rural Health, University of Kentucky; (5) Community Partner; (6) Community Partner, Appalachian Regional HealthCare

### What Is the Purpose of this Study/Review?

- To figure out how to best engage persons living in rural communities with neurological conditions such as stroke, traumatic brain injury, and spinal cord injury and their caregivers to be part of a research team.

### What Is the Problem?

- Little is known about how people in rural communities living with neurological conditions use research to make decisions about their health or how to engage this population to participate in research as members of a research team.

### What Are the Findings?

- The most effective method for engaging community members was to partner with already established and trusted community organizations.
- Persons with neurological conditions such as stroke, spinal cord injury, and brain injury and their caregivers value health research and want to be involved in developing research studies that will be most useful for their situations and communities.
- Barriers to participation include transportation difficulties, limited time availability, and lack of caregiving support.

### Who Should Care Most?

- Health care professionals, researchers, and members of community-based organizations who work with people with neurological conditions and their caregivers, particularly those in rural communities.

### Recommendations for Action

- Trust must be established before community members will be willing to engage with research.
- More investigation is needed to learn how to accommodate the various challenges faced by persons living with neurological conditions and their caregivers to allow them to more fully participate in research.