

Boston University Awarded PCORI Grant to Address Colorectal Health Disparities Among Autistic Adults

Boston, MA (August 12, 2025) — Boston University has been awarded a prestigious Patient-Centered Outcomes Research Institute (PCORI) Engagement Award to lead a groundbreaking national initiative aimed at improving colonoscopy access, participation, and patient experience for autistic adults. The two-year project will be led by Dr. Emily Rothman, Professor and Chair of the Department of Occupational Therapy at Sargent College, and involves collaboration with physicians, public health experts, and autistic self-advocates from across the United States.

Autistic adults face a disproportionately high burden of gastrointestinal (GI) conditions—including inflammatory bowel disease and Crohn’s disease—yet they are significantly less likely than non-autistic adults to receive colonoscopies, a critical diagnostic and preventive procedure. This project will address that inequity by building a national advisory board of autistic adults with colonoscopy experience and engaging them in the development of a patient-centered comparative effectiveness research (CER) agenda.

“Many autistic people face sensory, communication, and anxiety-related challenges when it comes to procedures like colonoscopy,” said Dr. Rothman. “This project is about ensuring their voices shape the future of GI health care research and practice.”

The project will use community-based participatory research methods to (1) train autistic adults in the fundamentals of patient-centered research; (2) conduct focus groups with autistic adults, GI physicians, and caregivers to understand barriers to colonoscopy for autistic people; and (3) co-create a research agenda that identifies the most urgent and actionable research questions related to improving colonoscopy experiences for autistic adults in the United States. Ultimately, the project aims to lay the foundation for large-scale CER study that improves outcomes for autistic patients.

Dr. Rothman’s Core Leadership Team includes Dr. Adam Stein, a GI specialist at Northwestern Medicine; Dr. Steven Lord, an internal medicine physician at Mt. Auburn Hospital in Cambridge, MA; and Scarlett Shiloh, an autistic patient advocate with personal experience navigating annual colonoscopies due to Lynch syndrome who is pursuing a master’s degree in public health from Boston University.

This project strengthens BU’s long-standing commitment to health equity and community-engaged research. It builds on Dr. Rothman’s track record of PCORI- and NIH-funded initiatives that have advanced inclusive practices in autism research and health promotion.

Boston Medical Center and the national nonprofit AANE (Association for Autism and Neurodiversity) are key partners on the grant and will assist with dissemination of the research agenda to clinicians, researchers, and policy leaders.

About Boston University

Founded in 1839, Boston University (BU) is a leading research institution with more than 34,000 students from 130+ countries. BU Sargent College of Health and Rehabilitation Sciences, of BU's 17 Colleges with its 92 full-time faculty and 1800 students, is world renowned for its translational research and training of health care professionals. BU's commitment to research excellence and community engagement is central to its mission to generate knowledge and improve society.

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