**BOWEL INCONTINENCE**

Many people live with chronic loss of bowel control (also called bowel incontinence, fecal incontinence and accidental bowel leakage – which is the involuntary passage of solid or liquid stool or mucus from the rectum). Between 7 to 15 of every 100 adults living in the community experience bowel/fecal incontinence. Because this condition is often associated with embarrassment, about 70% of patients do not talk about it with their doctor.

**If you are a caregiver or individual living with bowel/fecal incontinence, your voice is important to us.**

This is not a research study – we are developing a group of patients, caregivers, researchers and clinicians committed to identifying topics that can improve care and quality of life for people with bowel/fecal incontinence. Our focus is to better understand how bowel incontinence is talked about and treated in primary, community-based healthcare. Our group will help identify which research questions should be priorities for improving care for people with bowel incontinence.

Please consider learning more by visiting our webpage at: <http://osteopathic.nova.edu/ori/patient-centered-outcomes.html>, emailing Dr. Nicole Cook at nc570@nova.edu, or calling 954-262-1505.

\* This is not a research study. Participation is completely voluntary and can be via email, phone or conference call. A small stipend in the form of a gift card is available for patients and caregivers who participate in the Fecal Incontinence in Primary Care Consortium. \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Resources for patients and health care professionals can be searched on the internet under the title: “The NIDDK Bowel Control Awareness Campaign”, “ACOG accidental bowel leakage” and “IFFGD about Incontinence”:

# <https://www.niddk.nih.gov/health-information/health-topics/digestive-diseases/bowel-control/Pages/ez.aspx>

<http://www.acog.org/Patients/FAQs/Accidental-Bowel-Leakage#why>

<http://www.aboutincontinence.org/>

Dear [Recipients name]

It is my pleasure to invite you to participate in the Fecal Incontinence in Primary Care consortium, funded through a PCORI Tier 1 award**. The consortium seeks to bring together patients, researchers, clinicians and stakeholders who are committed to primary care comparative effectiveness research (CER) that will improve the quality of life for people living with fecal incontinence**. A summary of the project is here: <http://www.pcori.org/research-results/2016/fecal-incontinence-primary-care-consortium-tier-i>

Advisors to the consortium currently include Mr. Bill Norton, Mrs. Nancy Norton and Ms. Tegan Gaetano from IFFGD, Dr. Gena Dunivan from the University of New Mexico, Dr. Andrew Brickman, Dr. Sweta Tewary and Ms. Ludmilla Paul from Health Choice Network, Dr. William E. Whitehead from the University of North Carolina at Chapel Hill, Dr. Heidi W. Brown from University of Wisconsin, Michelle Goldberg, Stephanie Petrosky from Nova Southeastern University-College of Osteopathic Medicine, Dr. Angela S. Garcia from University of South Florida; and Matthew Slingbaum, Dr. Nicole Cook, Johanna Segura Restrepo from Nova Southeastern University Master of Public Health Program.

For the consortium to be successful, we recognize how important it is to include your expertise. Please consider this request to become involved in one of the following ways:

1. **Advisor** – Frame the mission; identify and support recruitment and involvement of the patient-centered learning community; and, provide expertise towards developing a CER topic portfolio. Advisors will participate in 3 phone meetings and will review and provide feedback on the portfolio via email. Anticipated commitment 6-8 hours per year.

2. **Subject Matter Expert Reviewer** – review a draft CER topic portfolio and provide feedback on the feasibility and relevance of topics to primary care practice and science via email. Anticipated commitment 1-2 hours per year.

Thank you for your expertise and for your support towards improving quality of life and treatment for persons living with fecal incontinence. Please respond to me or to Nicole Cook (at nc570@nova.edu or via phone at 954-612-6511) if you will accept this invitation.

Warm regards,