**Primary Care in Fecal Incontinence**

Minutes from First Committed Partners meeting: September 13, 2016

1. Introductions of Committed Partners
   * **Nova Southeastern University, MPH program**: Nicole Cook, Assistant Professor; Johanna Segura Restrepo, MPH student and FI Consortium Project Coordinator
   * **IFFGD:** Bill Norton, Vice-President; Nancy Norton, President and Founder; Teagan Gaetano, Program Director
   * **University of New Mexico:** Gina Dunivan
   * **Health Choice Network:** Andy Brickman, Executive Director Strategic Clinical Initiatives; Sweta Tewary, Research Data Analyst: Ludmilla Paul, Research Program Coordinator
2. Review of Goals of project and Committed Partner role.

* Everyone on the call reaffirmed their commitment to support the development of a patient-learning community that will support development of CER topics for community-dwelling persons living with FI who receive primary health care.

1. Review of Consortium name

* Decided to leave name “FI in primary care consortium” as is for now. Will revisit in future “FORTITUDE” and “PARTNERS” names proposed by Dr. Dunivan.

1. Consortium Governance structure.

* Will maintain a loose structure as consortium is further defined. Will revisit structure again as we learn more about PCORI expectations.
* Committed partners will be known as “Advisors”.
* Project Coordinator – Johanna Segura Restrepo, MD

1. Reviewed proposed missing and vision:
   * Noted that should include the concept of need to recognize importance of condition in the mission.
   * Nicole said that we would work on a draft and share with Advisors for review and comment.
2. Building the consortium and outreach: researchers, providers, patients, health policy and health finance, health information technology
   * It was determined that Advisors would like to think about who they will ask. Johanna and Nicole will provide elevator speech and introduction letter to be used for recruitment, and follow-up individually with each Advisor.
3. Throughout the one-hour call there was discussion about gaps in care and research topics important to the Advisors. These have been carefully reviewed and organized into the following research ideas:
   * *Would education/awareness of primary care providers (PCP) about prevalence of FI and options for managing FI improve patient health outcomes and/or quality of life?*
     1. There was discussion that PCPs 1) do not understand FI and/or treatments that can be provided in PCP, and 2) are currently overloaded with management of chronic diseases and other requirements and may not be open to additional screening/services.
     2. There was discussion about if providing education would raise awareness and if this would lead to more discussion/screening/management in primary care.
   * *How would improving communication around FI in primary care impact 1) earlier diagnosis and treatment and 2) quality of Life for patients*
     1. Advisors discussed an interest in understanding how better communication about FI in primary care could potentially lead to earlier treatment and/or better quality of life; improved health outcomes.
     2. Advisors discussed the issue of trust related to patient-provider community. For example: If patients with FI have a more trust in their provider, would they be more likely to discuss their symptoms with their provider?
     3. There were analogies between impotence and colorectal cancer screening and FI. Advisors discussed ideas related to improving communication between patients and providers, which perhaps could be facilitated by medicalizing terminology. It was discussed that most patients do not discuss FI with them provides and live with it on their own. It was noted that patients/providers may feel more comfortable talking about FI with their PCP if the terminology was more medical in nature (which may reduce embarrassment/discomfort.)
   * *How do treatments that can be provided in primary care compare to other treatments provided by specialists in terms of health outcomes and quality of life?*
     1. AHRQ March 2016 report “Treatments of fecal Incontinence” found no treatments that are comparatively more successful than other. One study suggested that PCP type of intervention (e.g. dietary fiber, modifying drugs and advice) were comparable to biofeedback.
   * *How common is FI among community-dwelling adults?*
     1. There was discussion about how most people in the community do not understand how prevalent FI is and that this can influence awareness about seeking care. Patients may feel that FI is a “normal part of aging” and that there is little that their doctor can do to help them. Advisors discussed that improved awareness of prevalence may improve care seeking behavior (and improve provider awareness.)
4. Recap of call. Nicole noted that we had a large agenda with introductions and several topics to cover. She reaffirmed her commitment to do everything possible to maximize each person’s time, energy and expertise as efficiently as possible to support the Consortium’s goals. Bill summarized the meeting: *“We have the same goals; we are in the same page. We are sensitive to the patient’s needs, we are outcome science driven. We all understand how important is to move a field forward. We have to satisfy everybody needs somehow”*
5. The first consortium meeting was adjourned at 3:05pm