

Original Article

## Nutrition Center of Excellence (COE) in Inflammatory Bowel Disease—A Model and Rationale for Development

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### Abstract

**Goals:** The goal of this study was to develop a multi-disciplinary consensus of nutrition care priorities for implementation in an IBD nutrition center of excellence (COE).

**Background:** The role for nutrition care in inflammatory bowel disease is broad and encompasses multiple domains. Gaps exist in the published literature around best nutrition care practices in inflammatory bowel disease and highlight the need for an evidence based approach acceptable to patients, and generalizable to a wide inflammatory bowel disease population.

**Study:** Twelve health leaders in inflammatory bowel disease care attended a 1-day retreat. Two focus groups were completed using traditional focus group methodology for the first half of the retreat and a World Café method for the second half. Data analysis included review of analytic memos and conceptual analysis completed at the time of discussion, theme identification and team consensus for conceptual development.

**Results:** Three primary themes were identified as the main pillars of a COE in an IBD nutrition center of excellence. These include: a) excellence in clinical care, b) novel discovery and research, and c) knowledge translation to patients and practitioners. The key initial steps identified in this study included standardizing malnutrition screening and support while creating an environment where nutrition therapy is included as a standard of care, developing and examining the effectiveness of novel diet therapies, and translating knowledge to build capacity among care providers and patients.

**Conclusions:** Using a 1-day retreat to identify a future direction for a center focused on nutrition excellence and align our coalition towards common goals was a successful strategy to develop consensus and identify nutrition care priorities for action.

**Keywords:** *nutrition care; inflammatory bowel disease; knowledge translation*

The relationship between dietary intake and the gastrointestinal tract (GI) in inflammatory bowel disease (IBD) has prompted investigation on two fronts: identifying and managing malnutrition and using dietary therapies to prevent and manage disease. Malnutrition is estimated to occur in 65% to 75% of patients with Crohn's disease (CD), and in 18% in 62% of patients with ulcerative colitis (UC) (1). Predisposing factors toward malnutrition include food avoidance and inadequate energy intake

due to symptom exacerbation, micro- and macronutrient malabsorption, increased basal energy expenditure as a result of active inflammation, and medication side effects (2).

Malnutrition related to reduced food intake and nutrient malabsorption is linked to altered body composition and sarcopenia. Sarcopenia is characterized by progressive and generalized loss of skeletal muscle mass and strength with adverse impacts on clinical outcomes including decreased quality of life,

increased postsurgical morbidity and mortality, and osteopenia (3). Identifying IBD patients who are malnourished remains a challenge due to lack of accurate nutrition screening and assessment tools able to identify malnutrition risk.

The European Society for Clinical Nutrition and Metabolism guideline recommends that IBD patients in remission should receive a nutrition care plan designed by a registered dietitian (RD) as part of a multidisciplinary approach to improve nutrition-affected outcomes (4). In clinical practice, this recommendation is impractical due to limited public access to RDs and the frequently prohibitive cost of private RD consultation. Consequently, nutrition prioritization tools are needed to identify IBD patients at high risk for malnutrition and sarcopenia who would benefit from personalized nutrition care. Furthermore, the effectiveness of screening and personalized care plans on long-term clinical outcomes needs to be established.

Over the past two decades, researchers have explored the impact of dietary interventions in either inducing or maintaining remission in IBD (5). For example, exclusive enteral nutrition has consistently induced remission in pediatric patients with CD; however, once a liberal oral diet is reintroduced, the maintenance of remission is frequently lost (6, 7). Much of the published literature on dietary interventions in IBD has focused on supplementing single nutrients, such as dietary fiber, omega-3 fatty acids and probiotics, with little focus on dietary patterns. Chiba et al. (8) investigated the role of a semivegetarian diet on preventing relapse of CD in patients. In patients who adhered to the prescribed diet for two years, remission was maintained in 92%, compared with 33% of patients in the omnivorous group. Another prospective dietary study explored the effectiveness of a specific carbohydrate diet (i.e., excludes all grains and sugars except for honey, processed foods and dairy except for yogurt and some hard cheese) in pediatric patients with active mild to moderate IBD (9). Disease activity decreased significantly following 12 weeks of dietary intervention, and C-reactive protein normalized. With the exception of these small prospective controlled trials, there is insufficient RCT data regarding effects of dietary patterns on intestinal inflammation to make evidence-based dietary recommendations for IBD.

The goal of this study was to develop a multidisciplinary consensus of nutrition care priorities for implementation in an IBD nutrition center of excellence (COE).

## MATERIALS AND METHODS

### Ethical Consideration

The Conjoint Health Research Ethics Board (CHREB) at the University of Calgary approved the study (ID: REB17-0758). Participants provided written consent to participate in the study.

### Study Participants

To identify nutrition care priorities for implementation in an IBD nutrition COE, 12 health care professionals in Calgary, Alberta, were invited to attend a full day retreat and participate in two focus groups. The first half of the retreat (focus group one) used focus group methodology to generate a list of priorities for the IBD nutrition COE, and the second half of the day (focus group two) was designed to develop an action plan to implement the identified priorities. One facilitator led the morning session to generate a list of priorities, and the afternoon session was led by a different facilitator to narrow the focus and develop actionable items. Participants included two gastroenterologists who were physician nutrition experts, four RDs, a director of nutrition services, a registered nurse, an IBD nurse practitioner (NP), a GI nurse manager, an occupational therapist and a social worker. Participants were purposively selected as having experience in providing care to patients with IBD and knowledgeable regarding access to nutrition care in the region. Participants were viewed as decision makers in their organizational contexts. Although none of the participants were patient representatives, we recognize the importance of involving patients as leaders in shared decision-making, and future building from this work would include a patient presence. Experience with providing nutrition care to IBD patients ensured a basic understanding of the care currently available to IBD patients and the ability to recognize potential gaps in service and knowledge. Figure 1 demonstrates the flow of the retreat, data interpretation and analysis.

### Focus Group One

A morning focus group was conducted to obtain a comprehensive understanding of nutrition care experiences, opinions and concerns in ambulatory and admitted IBD patients using a semistructured interview guide (10). At the beginning, the goals of the meeting were reviewed. Following this, the facilitator discussed the following: the contents of the information letter pre-circulated to participants, the background and rationale for the current work, focus groups guidelines, such as allowing all ideas to be shared in a non-judgmental manner, and the focus group questions. Three questions were included: 1) how to define excellence in nutrition care for patients with IBD; 2) a description of specific care gaps in nutrition care with discussion of strategies to minimize these gaps; and 3) identification of essential resources required to address the nutrition care gaps. Another research team member with experience in qualitative methodology recorded the discussion using analytic memos to identify concepts and patterns emerging from the discussion (11). The memos were reviewed by an independent facilitator who further developed the data into concepts over the designated break. All feedback from participants were included. These concepts were then presented and refined during the second half of the retreat in focus group two.

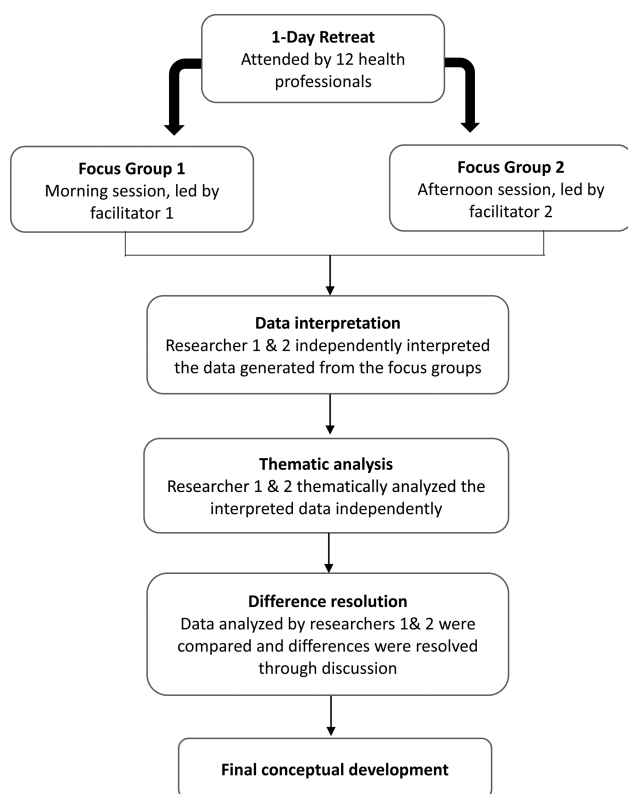


Figure 1. Flowchart illustrating the process of data collection and analysis. Data collection and analysis study flowchart. Focus group data collection process used to identify nutrition care priorities from 12 health professionals. Final conceptual development identified three themes as areas for further action. Figure boxes and arrows represent the order the steps occurred in the study process.

## Focus Group Two

Focus group two was held in the afternoon using a World Café approach to discuss action strategies for reducing gaps in nutrition care for IBD patients. World Café is a simple yet powerful participatory approach emphasizing the creation of a hospitable environment akin to a café-style ambience, in which individual and collective knowledge and ideas can be shared in small groups and then shared with the larger group (12).

The three-hour World Café session was divided into two sessions including development of an action plan and identification of potential challenges with mitigating strategies. Participants were asked to consider the concepts identified in focus group one and answer the following points: 1) envision three years from now and imagine excellence in nutritional care for IBD patients has been achieved; 2) describe the tangible steps taken to achieve excellence; 3) list stakeholders involved to reach this outcome; and 4) identify the strategies used to mitigate the challenges. In each session, the facilitator asked participants to discuss concepts in rotating small groups of three to four participants to encourage openness and sharing of ideas. Three minutes were allocated to discuss each question and record ideas. Following this allocated time period, one

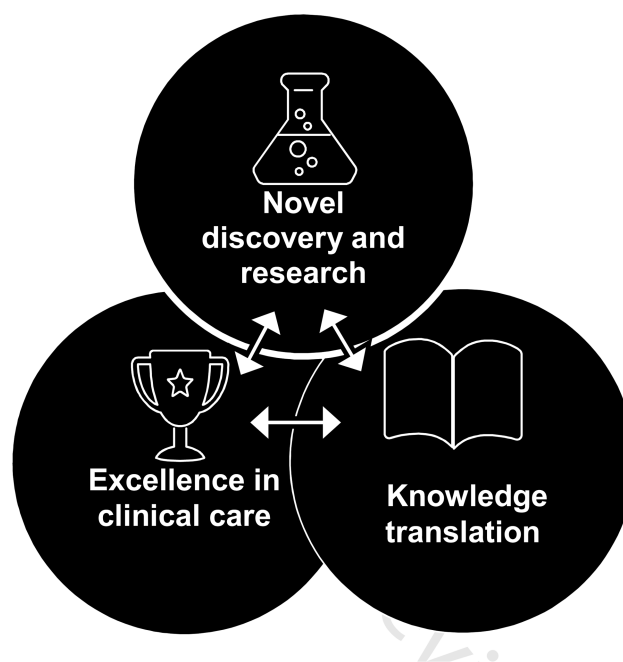


Figure 2. Diagram of three interrelated themes identified from the focus groups.

member from each small group presented the ideas to the larger group, and these were recorded on flip charts. The facilitator concluded the World Café by summarizing responses from the small groups and obtaining consensus from participants on identified concepts and actionable items. As with the morning session, analytic memos were used to capture the afternoon discussion. These memos were sent to the World Café facilitator who added reflections before analysis.

## Data Analysis

Data analysis was completed using three steps. Initially, the facilitators of the sessions reflected on the analytic memos and conceptual analysis captured during the sessions. The two recorders from the sessions thematically analyzed memos taken during the sessions. The researchers identified main themes and organized concepts underneath these themes based on their independent interpretation of the data (10, 11). Each theme and conceptual definition was then compared between the two researchers, and conceptual differences were resolved through discussion using a consensus approach. Data were then examined to identify negative cases (i.e., constant comparative method), and these were discussed to add to the emerging conceptual development.

## RESULTS

Three interrelated themes emerged from the data to develop a multidisciplinary consensus of nutrition care priorities for IBD treatment. For a visual description, please see Figure 2.

### **Theme One: Excellence in Clinical Care**

Participants identified the need for evidence-based, personalized nutrition assessment and treatment provided as standard care to treat malnutrition when IBD patients present to manage symptoms and improve disease severity. An IBD NP said, "Patients are always asking us, 'What can I do to modify my diet to change my symptoms?'"

One of the major nutrition issues present in IBD treatment is the presence of untreated malnutrition. Malnutrition is frequently under-recognized and, consequently, untreated. Identifying patients at risk for malnutrition to carefully select patients who would most benefit from nutrition therapy was of high priority for participants. To do this, participants suggested the development of an easy to administer, accurate malnutrition screening tool to identify patients at high risk of malnutrition and sarcopenia. The IBD NP commented, "Patients are really good at checking boxes. Give them boxes to check so that the nutritional assessment is done". This tool would ideally be a reliable and acceptably valid malnutrition assessment sensitive to change over time and relevant to IBD outcomes.

The second suggestion was to increase accessibility to personalized nutrition therapy and to engage patients in the design and delivery of the therapy. Patient engagement was emphasized by a number of participants. For instance, a nurse educator mentioned, "Patients have to be the foundation or the focus because at the end of the day, I think honestly patients are what is going to drive our outcomes and our deliverables and also sustainability".

### **Theme Two: Novel Discovery and Research**

The second theme was the need to identify evidence to deliver effective personalized nutrition therapies for IBD management.

An RD said, "I think it's also important with providing services to inpatients and outpatients to provide them with opportunities to participate in novel therapies in terms of research". Participants identified that there is limited consensus on what optimal nutrition therapy for the IBD patient looks like. They felt more research is needed to develop the evidence base to support nutrition therapy as a strategy to improve disease severity and reduce inflammation before offering it as a standard of care (i.e., theme one) to patients with IBD.

Developing a research-training environment focused on clinical and translational nutrition research was identified as one strategy to incorporate research activities into daily practice. The recruitment of interested students and provision of support to secure graduate studentship funding were seen as important components to further the research agenda of the COE.

Initial research priorities included identifying and testing malnutrition screening tools with high-performance characteristics in inpatients and ambulatory settings and exploring the effectiveness of dietary therapies on IBD disease activity, mechanistic

impact on the gut microbiome and improvements in patient experience and health-related quality of life. This would be accomplished by actively seeking grant funding for projects focused on the priorities of the nutrition COE. According to an RD participant, "When I think of a COE, I see it as being kind of at the forefront for providing new treatments. . . ."

### **Theme Three: Knowledge Translation**

The third theme was to translate evidence-based standards of care and therapies generated in theme two to patients and practitioners. To build knowledge translation (KT), participants felt COE activities should be shared with all health professionals managing patients with IBD provincially and nationally. To ensure health providers were informed of advances in nutrition and its role in IBD management, the participants suggested the COE compile a list of partners including patient advocates, healthcare professionals, government, industry, academia, research, community and grant agencies to align COE activities with already existing projects, promote collaboration and ensure effective communication with key decision-makers in these organizations. To facilitate KT to these stakeholders, a variety of activities were suggested including formation of an electronic platform to provide a variety of KT activities, online nutrition education modules highlighting advances in nutrition therapy in IBD for all health professionals participating in IBD care, newsletters highlighting novel nutrition therapies and research, creation and circulation of evidence-based practice guidelines and best practices, implementation tools for nutrition care, a yearly stakeholder conference for key partners to network, collaborate and advance ideas, and development of patient nutrition resources.

An organizational leader said, "Making people more aware of what it is that we are doing and think about the CoE banner will really help to spread that message".

A nutrition research scientist emphasized the importance of knowledge translation by stating, "How do we ensure that we are showing the outcomes that funders and other individuals want to see in addition to our patients?"

Another strategy to translate knowledge was to develop formalized education opportunities including specialized nutrition rotations for GI trainees to participate in during their core GI training program. In addition, advance nutrition fellowships for GI trainees who have completed their core training would be offered through the COE, focusing on building and translating knowledge. A need for partnerships with dietetic programs to offer rotations for dietetic interns to increase knowledge and awareness of the unique nutrition issues experienced in patients with IBD was highlighted. A gastroenterologist suggested that "we should look at developing formal nutrition fellowships, analogous to what we do with IBD and hepatology fellowships." So it's building from core functions of a gastroenterologist and

actually writing specific objectives and training and expectations for what you would have to do beyond that to actually be able to say that you have expertise in this". An RD suggested, "It will be great as part of the centre to educate the other dietitians interested in the GI area. So that it's not just a few individuals in our province that are specialized in the area, but everybody can get the knowledge they want".

#### Barriers.

Barriers to advancing these three themes included concern for sustainable funding for COE activities, cost of additional clinical care, potential overlap with existing resources and lack of access to important infrastructure such as staffing, information technology platforms and space for students, researchers and practitioners to collaborate. Proposed solutions included dialogue with invested stakeholders to continually prioritize fundraising, engagement with nutrition care providers to align nutrition priorities within IBD to ensure lack of duplication, building early collaborations with information technology and university leadership in a deliberate manner, and creating value for all stakeholders to recognize advancing nutrition care for IBD patients.

## DISCUSSION

The primary objective of our study was to identify nutrition COE priorities to improve nutrition care, clinical outcomes and quality of life for IBD patients. Multidisciplinary healthcare providers, using focus groups and World Café methodology, identified three core themes. All participants agreed promoting excellence in clinical care for IBD patients is needed; novel nutrition research in IBD will inform these strategies, and translating new knowledge to trainees, health professionals and patient stakeholders will be essential to improve malnutrition and sarcopenia.

These steps closely align with Canadian Institutes of Health Research Guidelines for effective knowledge translation using the "Knowledge-to-Action Cycle" (KTA cycle) (13, 14). Knowledge creation is at the core of the KTA cycle and includes knowledge inquiry, leading to synthesis, which results in products and tools that can be used to address identified problems. In this study, we identified the core theme of novel discovery as a key component of a COE. For example, patients are interested in dietary therapies to independently manage or comanage their disease alongside traditional medical therapy (5) (i.e., knowledge inquiry), and while nutrition therapy in IBD patients has demonstrated improvements in clinical outcomes (i.e., knowledge synthesis), it is inconsistently addressed during routine IBD management (8, 15). As a result, identification of products and tools (i.e., effective nutrition interventions and guidelines) are needed to apply into routine clinical management of the

IBD patient (i.e., nutrition interventions enter the application or action phase of the KTA). As identified in the KTA cycle and our focus groups, knowledge creation is an essential component of a COE to identify best practice interventions and to develop clinical practice guidelines (13).

Theme one is excellence in clinical care, while theme three is knowledge translation, as described by the action cycle of the KTA process. For example, "prevalent malnutrition" was identified as a problem, and a screening program to identify malnourished patients was identified as a need for development. When reviewing the problem, participants agreed nutrition screening is not commonly performed in IBD outpatient settings (16–18). Considering the barriers to nutrition screening, the group identified that of the existing nutrition screening tools developed in other populations, the optimal screening tool either remains unknown or not yet developed. For example, a recent systematic review indicates body mass index (BMI) does not accurately predict body composition in IBD populations, and patients with normal or elevated BMIs may not be appropriately identified as at risk of malnutrition with traditional screening tools (19). As a result, to be able to implement an intervention (the next step in the KTA cycle), additional knowledge synthesis was needed to identify a clinically predictive nutrition screening tool for implementation in IBD clinics. Once identified in the knowledge creation process, the process of administering this screening tool can be adapted to the local context, barriers to implementation can be identified, and usefulness monitored and subsequently evaluated, if it leads to improvements in identifying patients with malnutrition. The action cycle of the KTA then begins again to implement personalized nutrition therapy; the second action item in the theme of excellence in clinical care and supported by the IBD European Society for Clinical Nutrition and Metabolism guideline advising optimal care includes a nutrition consultation for all IBD patients (4). By bridging the care gap and engaging stakeholders—including healthcare providers, patients, research institutes and policymakers—we can create an institutional culture that values nutrition as an essential component of IBD therapy.

The following actions are identified in theme three: knowledge translation focused primarily on assessing barriers to knowledge use, engaging stakeholders to implement interventions and monitor knowledge use and outcomes, and sustaining knowledge use by providing education and resources to health professionals and patients. The close alignment between our focus group findings and the KTA cycle supports using the KTA cycle to guide further knowledge inquiry and provides a structure for the development of the COE.

To build support for evidence-based IBD nutrition care, a virtual COE is under development in Calgary, Alberta, Canada. A number of priorities have been successfully identified as described in this study, and other centres may find using a

**Table 1.** Short- and long-term goals identified for the COE

Theme 1: Excellence in Clinical Care		Theme 2: Novel Discovery and Research		Theme 3: Knowledge Translation	
Short-term activities (1–3 years)	Long-term activities (5 years +)	Short-term activities (1–3 years)	Long-term activities (5 years +)	Short-term activities (1–3 years)	Long-term activities (5 years +)
1. Valid and reliable malnutrition screening tool identified.	1. Collect cost-effectiveness data on malnutrition screening and intervention.	1. Develop a comprehensive research program exploring novel dietary therapies to identify efficacy, mechanisms of action including impact on microbiome and metabolome, and subsets of patients with the highest likelihood to benefit from dietary interventions.	1. Develop sustainable funding and supervision model for graduate students	1. Stakeholder identification and partnership agreements.	1. Develop and distribute an online certification program for IBD nutrition therapy for RDs, nurse practitioners and gastroenterologists nationally based on nutrition practice guideline developed in partnership with CAG.
2. All IBD patients in Alberta screened for malnutrition.	2. Share outcomes of screening project nationally and internationally.	2. Continue to develop a comprehensive research program examining novel diet interventions and delivery systems.	2. Continue to develop a comprehensive research program examining novel diet interventions and delivery systems.	2. Development of an online platform for education for both professionals and patients.	2. Offer a yearly conference focused on nutrition advances and interventions for IBD patients.
3. If screened “at risk” patients will be assessed for micronutrient deficiencies and referred for a nutrition intervention.	3. If successful work with Canadian Association of Gastroenterology to translate into a Canadian practice guideline for nutrition screening and treatment.	3. Disseminate data nationally and internationally at CDDW and DDW conferences.	3. Disseminate data nationally and internationally at CDDW and DDW conferences.	3. Seek additional funding opportunities to support fellowships for GI trainees.	3. Evaluate outcomes of GI fellow and nutrition internships and share results and programming information nationally.
4. Clinical outcomes assessing effectiveness of screening and referral program collected.	3. Develop a research training environment with graduate students.	2. Seek Tri-council and foundation funding to develop a research program focused in novel dietary therapies annually.	3. Develop a research training environment with graduate students.	4. Offer nutrition fellowships for GI trainees.	
				5. Implement dietetic intern rotations focused on nutrition therapy in IBD.	
				6. Work with the Canadian Association of Gastroenterology to form special interest group in Nutrition and develop nutrition practice guideline based on consensus.	
				7. Identify and develop patient nutrition focused resources including online resources.	

similar process, strengthened by considering how the KTA cycle can guide inquiry, beneficial to identify local priorities to further a nutrition agenda. The next step for the nutrition COE after completion of this study was to design a strategic plan to identify short, medium and long range actions in line with the priorities for action identified in this study (Table 1). For example, in the months following the focus groups, the COE team successfully applied for internal research grants to support knowledge creation activities for novel nutrition therapies and mobilized student volunteers to conduct a cross-provincial study examining the performance of available malnutrition screening tools in IBD.

The primary goal of the COE is to influence nutrition care for digestive diseases at national, provincial and local levels within the existing infrastructure. A virtual approach will be used to meet the COE goals in Alberta. This means the COE is comprised of provincial members, has a provincially based governance structure and does not have a centralized location. Benefits of a virtual entity include lower operational costs, greater allocation of funding to staff with the highest level of skill and not limited by geography, and the involvement of health professionals from multiple sites to better capture the full spectrum of care. Some of the challenges of this model are deciding where financial resources are centered, how they are accessed, and how to gain support from institution leads who are contributing current infrastructure support. Results from this study are limited by the perspectives of the participants and were developed with a provincial and Canadian national context. The methods used to develop COE objectives, however, are generalizable and could be used to further develop nutrition priorities in different settings.

In conclusion, this study supports the use of the KTA cycle to guide development of priorities for action in this context and suggests that using the KTA cycle to help guide discussion may be a useful tool to increase the richness of the data. Results from our study suggest other groups may benefit from using the KTA cycle to customize their approach and identify key initial steps for action. The key initial steps identified in this study included standardizing malnutrition screening and support, while creating an environment where nutrition therapy is included as a standard of care, developing and examining the effectiveness of novel diet therapies, and translating knowledge to build capacity among care providers and patients. Other centres can use these results and, if applicable to their context, may benefit from using a similar study design.

## ACKNOWLEDGEMENTS

The authors would like to recognize Nutrition Services, Calgary Zone, for their continued support and hard work with the COE. They would also like to recognize the focus group participants who dedicated their time and extensive expertise to the development of the COE. This

work was supported by Shire Canada. Authors' contributions: NS, LT and MR were involved in all aspects of study design, data acquisition and analysis, drafting and critically reviewing the manuscript, and approving the final version to be submitted.

PT and RP were involved in conception and design of the study, critically reviewing the manuscript for intellectual content and approving the final version to be submitted.

**Conflicts of Interest:** The authors have no conflicts of interest to report.

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