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Observations and Research

Patient Advisory Groups in Inflammatory Bowel Disease: A Collaborative Relationship Between Patients and Researchers

Linda Yoo, MS, RN,[*] Mara Shapiro, BA,[*] Ihsan Kahveci, MA,[†] Isabela Hernandez, BS,[‡] Rachael Whittemore, MSPAS, PA-C,[§] Tanvi Kale,[*] Samantha Winders, PhD, RN,[*] and Kendra Kamp, PhD, RN[*]

[*]University of Washington School of Nursing, Seattle, WA, USA
[†]Department of Sociology, University of Washington, Seattle, WA, USA
[‡]University of Miami Miller School of Medicine, Miami, FL, USA
[§]Valley Health Surgical Oncology, Winchester, VA, USA

Address correspondence to: Linda Yoo, MS, RN, University of Washington School of Nursing, Box 357260, Seattle, WA 98195, USA (lhy4@uw.edu).

Background: Patient advisory groups are key to guiding research studies through meaningful engagement with the population of interest. Although patient advisory groups are greatly valuable to research studies, they are underutilized in inflammatory bowel disease research. Thus, this study aims to describe the development and implementation of a patient advisory group and evaluate the perspectives of researchers and members.

Methods: The Comprehensive Self-Management for inflammatory bowel disease study patient advisory group was created in 2022. The patient advisory group members and researchers completed the Public and Patient Engagement Evaluation Tool via an online survey. Thematic analysis of responses was used to identify common themes, and descriptive statistics were reported.

Results: The patient advisory group comprised of patients with inflammatory bowel disease met quarterly. Eight members and three researchers evaluated the patient advisory group. The five emerging themes were (1) lived experience of patient advisory group members; (2) diversity and representation; (3) purposeful engagement; (4) positives of patient advisory group; and (5) improvements to patient advisory group. All members agreed or strongly agreed that the meetings were a good use of their time, and all researchers strongly agreed that the group added value to the research study.

Conclusion: Patient advisory groups can create unique and positive experiences for both members and researchers when feedback is meaningfully sought, intentional, and incorporated into the study. There is a need to continue creating and using patient advisory groups with the intention of identifying problems and finding solutions alongside the inflammatory bowel disease community.

Lay Summary

Patient advisory groups (PAG) can create a positive collaborative experience for researchers and patients in inflammatory bowel disease (IBD) research when feedback is meaningfully sought and intentional. PAGs in IBD should be utilized to identify problems and find solutions.

Key Words: inflammatory bowel disease, patient-centered research, patient advisory groups

Introduction

Inflammatory bowel disease (IBD), a chronic disease, is often related to poor quality of life and impaired work productivity.[1,2] The unique experiences and perspectives of individuals living with IBD are instrumental in creating research that reflects and supports patient needs. A patient advisory group (PAG) is a group of patients and/or caregivers who are committed to providing feedback and perspectives to advance research, clinical practices, and policies.[3] PAGs are not only essential in establishing research priorities and improving policies but also necessary in creating and executing patient-centered research.

The acceleration of innovative research using a patient-centered approach has been outlined by foundations, funding agencies, and researchers. For instance, all five research priority areas from the Crohn's and Colitis Foundation (CCF) 2024 Challenges in IBD Research are focused on a key principle of patient centricity.[4] Additionally, the top 10 research priorities for children and young adults highlight a patient-centered research agenda.[5] Concerns regarding declining recruitment and lack of diversity in IBD clinical trials pose an opportunity to address the unmet needs of those with IBD, reconsider current research practices, and improve the research experience for IBD participants to improve equity and inclusion in IBD research.[6] One way to improve patient-centered IBD research is to utilize PAGs. Pilot studies, such as those on physical activity in IBD, have briefly mentioned the use of PAGs.[7,8] However, despite the importance of PAGs, there is a scarcity of literature that explores PAGs in IBD research and how researchers and individuals with IBD can work together

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to improve IBD research.[9] Thus, it is necessary to consider the roles of patient voices in IBD research and ways we can improve our approach to patient-centered research.

The Comprehensive Self-Management for IBD (CSM-IBD) study is a pilot randomized control trial study for an eight-session intervention on topics related to IBD self-management, such as problem-solving, pain management, and symptom tracking.[10] A PAG was created for the CSM-IBD project with the intentional goal of collaborating with IBD patients. This PAG can provide a potential exemplar for future IBD research studies, especially in IBD intervention creation. IBD patients can provide an important perspective on the research process, making research more approachable, improving study satisfaction, and decreasing barriers for study participants. After being established for nine months, CSM-IBD researchers and members sought to understand the impact of the PAG on both members and researchers as well as to identify potential areas of improvement. Thus, the aims of this study were (1) to describe the development and implementation of a PAG and (2) to evaluate the PAG from the perspective of both researchers and members.

Materials and Methods

This study describes the development and implementation of a PAG using the CSM-IBD as a model. The development of the PAG and details regarding meeting scheduling and structure are described. The PAG was established in 2022 and was composed of 10 members and 3 researchers. The group met for three quarterly meetings from November 2022 to May 2023. In August 2023, PAG members and researchers were invited to complete an electronic survey via REDCap, a secure data collection and management software.[11,12] Participants were compensated $25 for completing the survey. Survey questions were based on the Public and Patient Engagement Evaluation Tool (PPEET) project questionnaire with modifications and additions to fit the population of interest.[13] The PPEET can be used to evaluate ongoing/long-term activities and includes both a 5-point Likert scale and open-ended questions focused on examining the engagement of PAG members and researchers. The PPEET allows for the evaluation of communication and support for participation, sharing views and perspectives, and the impact and influence of the PAG. The 5-point Likert scale questions are listed in Table 1.

Demographic and IBD health information were also collected. Data collection of the researchers and PAG members was IRB exempt as per the University of Washington Human Subjects Division. Both researchers and PAG members were invited to contribute to the manuscript. Thematic analysis was performed on qualitative data from open-ended questions. Two reviewers started by immersing themselves in the data. Preliminary codes were independently created by the two reviewers; then, the reviewers discussed, revised, and organized the codes through an iterative process. For the quantitative data, descriptive statistics were used to report demographics, IBD health information, and the PPEET 5-point Likert scale questions.

Patient Contribution to Research

This research project collaborated with the members of the PAG from the project's conception. PAG members actively provided feedback on the project, and specific members provided in-depth insight and feedback on ways to improve the project. Researchers and PAG members worked together during data analysis and dissemination of information from this project, including manuscript writing. The progress of this project and updates were reported to all PAG members during the quarterly meetings, and the researchers actively encouraged the participation of PAG members in the many elements of the project.

Results

Developing the PAG

Our PAG was created by identifying IBD patients through local gastroenterology (GI) clinics in the Pacific Northwest and through a nonprofit IBD organization: the Crohn's and Colitis Young Adults Network. Individuals could participate in the PAG if they were adults (aged 18+) with IBD. We sought to create a group with diverse backgrounds and experiences, including those with and without clinical trial experiences, varying disease history and experiences, and demographics. For clinic patients, we emailed eight individuals and invited them to participate in the PAG (see Supplementary Table 1 for email invite information). We included an overview of the PAG, their role, the time commitment, what's in it for me, and the next steps in the initial email. Five individuals were interested in participating. For the Crohn's and Colitis Young Adults Network, five individuals expressed interest in participating after receiving information regarding the PAG via email. PAG members were not participants in the CSM-IBD study. A total of 10 IBD patients and 3 researchers comprised the CSM-IBD PAG.

PAG Meeting Structure

The PAG members and researchers met quarterly via a video conferencing platform. Researchers selected several possible dates and then sent a scheduling email approximately four weeks in advance to determine the day and time that worked the best. Due to coordinating multiple schedules, we aimed for the day with the greatest availability, knowing that not everyone would likely be able to attend. The PAG meetings were moderated by a researcher with IBD and followed a set agenda that was developed ahead of time by the researchers (see Supplementary Table 2). The researchers created a PowerPoint presentation to guide the conversation. PAG members could communicate verbally by unmuting themselves or through text in the video conference platform chat box.

The meetings began with an overview of the agenda, introductions, and expectations on the conduct of both the researchers and members. Then, the researchers provided updates on the CSM-IBD study and transitioned to a discussion with members on topics of interest related to the study, such as recruitment and retention, stool sample collection, future research interests, and data collection methods and preferences. During the meetings, there were opportunities for PAG members to ask questions and discuss other relevant topics related to IBD research. PAG members provided feedback on the study at every PAG meeting. After the meeting, the researchers worked to incorporate the feedback from PAG members into the CSM-IBD study. The researchers updated the PAG members at the next meeting on how their feedback was utilized in the CSM-IBD study. For example, researchers

Table 1. Quantitative findings of PAG members and researchers.

Questions	Strongly agree or agree *N* (%)
PAG members (*N* = 8)	
I have a clear understanding of the purpose of the patient advisory group (PAG)	7 (87.5%)
Format of the PAG meetings are accessible	8 (100%)
I have enough information to contribute to the topic being discussed	7 (87.5%)
I am able to express my views freely	8 (100%)
I feel that my views are heard	8 (100%)
A wide range of views on the topics discussed are shared	8 (100%)
The individuals participating in the PAG represent a broad range of perspectives on the topic	7 (87.5%)
I think that the PAG achieves its objectives	8 (100%)
I am confident the input from PAG members provided through this initiative are used	6 (75%)
I think the input from PAG members provided through the PAG meetings are making a difference to the work of the study	8 (100%)
As a result of my participation in PAG, I am better informed about IBD research	6 (75%)
Overall, I am satisfied with the PAG*	7 (87.5%)
The PAG meetings are a good use of my time	8 (100%)
PAG researcher (*N* = 3)	
The perspectives of those who will be most affected by the outputs of the IBD CSM PAG were reflected through those who participated in the engagement	3 (100%)
The financial, logistical and information needs of participants (eg, travel, dietary, interpretive, childcare, etc.) were accommodated	3 (100%)
Adequate time was allocated to plan and implement the IBD CSM PAG	3 (100%)
The goals for the PAG were shared with participants	3 (100%)
Participants were told how the input from IBD CSM PAG meetings would be used by the IBD CSM study	3 (100%)
Overall, I was satisfied with the engagement of the IBD CSM PAG	3 (100%)
The IBD CSM PAG added value to the IBD CSM study	3 (100%)
As a result of my involvement in the IBD CSM PAG, I will be comfortable leading future activities related to patient advisory groups	3 (100%)
I think that the IBD CSM PAG achieved its objectives	3 (100%)
I would be interested in getting specific training to build my capacity to do more of this work	3 (100%)

*n = 1 missing data.

gained feedback on stool sample collection. PAG members discussed the difficulties of stool sample collection when using a small collection device or wooden tongue depressor. Based on this feedback, the researchers brainstormed alternative collection devices and then updated the stool sample collection materials by providing a large separate sterile spoon for participants. Additionally, a trash bag, gloves, and hand sanitizer were included based on our discussion. Changes to the stool sample collection kit were presented to the PAG at the following meeting. Other items for the study were refined with the feedback of PAG members. For example, additional extraintestinal symptoms were added to symptom measurement, and flyers for recruitment were reviewed and altered to be more appealing. The researchers also shared with PAG members preliminary data and discussed potential research questions for the future.

After each meeting, PAG members were compensated $50 for one hour and provided with meeting notes. Members were also sent an anonymous feedback forms following each meeting. Communication with PAG members was through email. Annually, PAG members were asked about their interest in continuing their engagement in the PAG and given the opportunity to conclude their involvement. Figure 1 provides information on each of the PAG meetings to date, including information on the content covered in the meetings.

Evaluating the PAG: Perspective of Members and Researchers

Out of 10, 8 PAG members and three researchers completed the anonymous survey after nine months of participating in the PAG. Of the members, six had Crohn's disease, and two had ulcerative colitis. The average length of IBD diagnosis was 11.9 years (SD: 7.2). Most PAG members were between the ages of 18 and 30 (n = 5, 62.5%), employed full or part-time (n = 7, 87.5%), and had inactive disease (n = 5, 62.5%). Only 1 member had experience in a previous PAG. Overall, most PAG members and researchers strongly agreed or agreed with survey items on communication and support for participation, sharing views and perspectives, impacts and influence of engagement, and satisfaction with the PAG (Table 1).

Additionally, members and researchers responded to open-ended questions regarding their experience, which led to five main themes (description): lived experiences of PAG members (the unique and invaluable benefit of having patient

Figure 1. Timeline of PAG meetings and content.

perspectives and thoughts in the research process), diversity and representation (a diverse group of members in terms of both personal and IBD-related backgrounds and continued efforts to solicit more varying thoughts and perspectives on disease experience and severity), purposeful engagement (researchers were interested and considered members' opinions as important, and actively implemented the advice of PAG members), positives of PAG (meetings were organized and easy to participate in, and members learned from listening to others at the meeting and felt connected), and improvements to the PAG (difficulties with large group size in discussions and the online format, and clearer information on roles and expectations). Figure 2 provides the thematic map with the main and subthemes.

The following are representative quotes from PAG members related to their experiences with the CSM-IBD PAG.

> "I really hope this PAG and the following research about it will help show the IBD field and even more chronic disease communities that patient insights matter and are vital to creating impactful research." (PAG member)
>
> "… I do feel confident that the research team will integrate our perspectives in a way that will help another patient." (PAG member)

Discussion

There is an urgent need to embed patient-centered practices into IBD research. In patient-centered clinical practice, clinicians and patients work collaboratively on decision-making related to treatment plans that are tailored and appropriate for the lifestyles and backgrounds of patients. This allows for patients to be active in their care. However, within IBD research, patients are rarely provided the opportunity to partner with researchers in developing research questions, establishing priorities, and participating in the research process. One method of incorporating patient voices is through the use of a PAG, which allows for collaboration between patients and researchers to transform research practices for the benefit of the patient. Based on the findings of this study, PAGs should be intentional and purposeful, with clear expectations that researchers will not only obtain the lived experiences and knowledge of those with IBD but also implement, follow through, and communicate how that knowledge was used in IBD research. Not only did PAG members indicate benefits from joining, but PAG researchers also stated the importance and positive impact of having patient feedback in the research process.

PAGs are especially valuable for clinical trials as participating in research poses a great burden to patients, which can impact overall participation.[6] Researchers can better retain study participants and improve study satisfaction for participants by problem-solving with the PAG (eg, multiple stool sample collections).[14,15] Additionally, improving diversity in clinical trials is necessary to create evidence-based practice guidelines that accurately reflect the IBD patient population and eliminate health disparities.[16] Not only does diversity in clinical trials need to consider race and ethnicity, but also older populations and gender-diverse individuals.[17] By engaging participants of varying backgrounds and experiences in PAGs, researchers can develop and implement recruitment strategies and research practices that are culturally sensitive and encourage participation in research of underrepresented subgroups in IBD.[18] Notably, PAGs take time and effort on behalf of the researchers to develop, solicit feedback, and incorporate that feedback into the research project. However, as noted by guidelines for increasing clinical trial diversity in IBD, investment in communities is an active process. Based on the five themes found in the study and literature, we provide a list of best-practice recommendations of ways researchers can create and facilitate PAGs in IBD research (Table 2). Some of these best practices include compensating members for their time, soliciting feedback, and intently preparing for the PAG meetings.[19]

Creating a PAG early in the research process can help create a patient-centered culture in IBD research. Patient voices should be the foundation of IBD research and require researchers to actively seek and appreciate feedback from IBD patients. IBD communities, such as ImproveCareNow, have successfully worked alongside patient advisory councils to generate new resources that are founded on the needs expressed by pediatric IBD patients and families.[20,21] A systematic review of patient and family advisory councils found that most patient groups in health research were limited to providing assistance in recruitment and retention rather than the many other elements in health research (eg, study creation, and dissemination of findings).[22] Thus, there is a current need to continue efforts to expand the role of patients in health research. A culture of mutual respect and partnership is pivotal to research that is created for the IBD community. There are unique challenges and considerations for IBD participants that can be addressed through PAGs. Within the process of finding solutions to research problems, IBD PAG participants can also find benefits from engaging in IBD research by learning more about the disease and building trust in the scientific research process.[23] Through this mutually

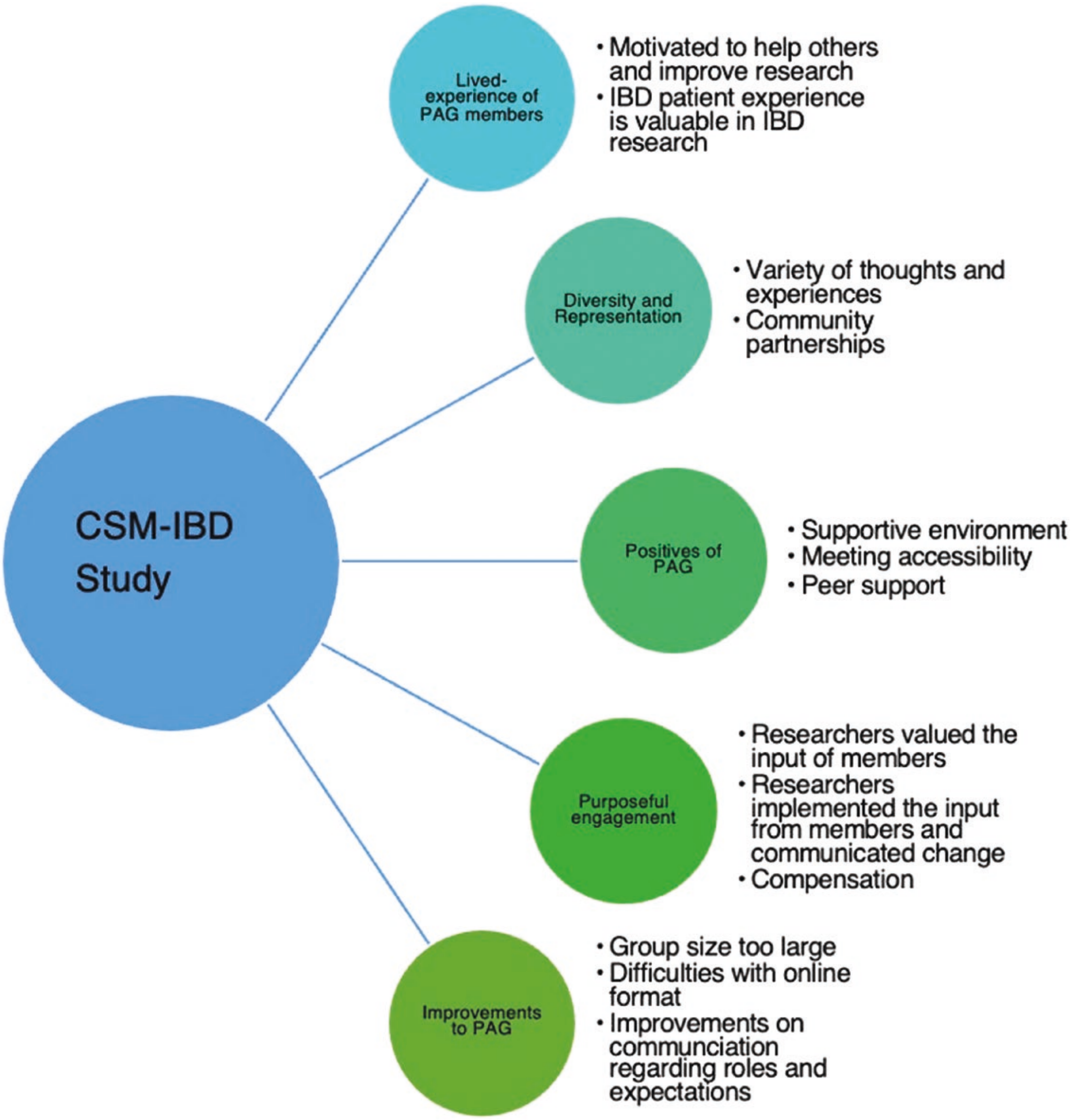

Figure 2. Thematic Map. Patient advisory group (PAG), inflammatory bowel disease (IBD).

Table 2. Best practices.

Patient Advisory Group Best Practices For Researchers
Create PAGs early in the research process and, ideally in research design
Set the agenda and prepare ahead of the meeting
Provide brief summaries and updates of the study during meetings
Reflect on what is going well/what is not going well in PAG
Solicit feedback from members on the PAG meetings, and ideally anonymously, to provide a safe environment to provide criticisms
Bring back how the information from PAG meetings is used, and listen to the interests of PAG members
Follow up with PAG members after the meeting on plans for future meetings, updates to questions, or action items from the meeting
Provide compensation for PAG members- monetary, opportunities for publications, collaborations
Ask PAG members what matters to them in their participation and give opportunities for members to reflect on what improvements could be made to the group and to the project as a whole

beneficial relationship between researchers and participants, the goal is to create meaningful research that is innovative and relevant to the lives of those with IBD.

Limitations

This study has a limited sample size as it only includes the PAG members and research team from the CSM-IBD study.

However, to facilitate a supportive environment, the small PAG size allows more interaction and involvement which fosters rich discussions. Qualitative data was obtained through open-ended survey questions to allow PAG members and researchers to anonymously express both positive and negative feedback about the PAG. The use of interviewing methods with follow-up questions to solicit feedback may have yielded further data from researchers and members. The IBD CSM PAG is composed of only English speakers; there is room for further representation of underrepresented groups, such as non-English speakers, with the evolution of the PAG.

Conclusions

PAGs provide an important avenue for a collaborative process between researchers, individuals living with IBD, community partners, and nonprofit organizations. Currently, most IBD research lacks PAGs, which is a missed opportunity for both the IBD community and researchers. Patients with IBD should be involved in creating research that is most intriguing and important to their daily lives. Additionally, there is a need to improve IBD study participation by reforming current research practices and procedures to make research participation fun and convenient. Members of PAGs should be compensated for their efforts and provided opportunities for academic publications and presentations. IBD research is better when the voices of individuals who live with IBD are given a seat at the table. Researchers should make thoughtful efforts to value patient perspectives throughout the entire research process, starting in the early phases of research design.

Supplementary Material

Supplementary data are available at *Crohn's & Colitis 360* online.

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Conflicts of Interest

No financial disclosures or conflict of interest by authors.

Data Availability

Data is available on request.

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