

Research in Inflammatory Bowel Disease – The Patient's Perspective

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BACKGROUND

Although research plays a critical role in advancing the management and care of patients with IBD, there are few studies describing patients' views relating to IBD-related research.

This study aimed to assess patients' views on study participation, research areas of importance, and use of personal data.

METHOD

Patients attending an IBD educational event, which was organised by the INITIative research network in collaboration with the Irish Society for Colitis & Crohn's Disease (ISCC), were asked to complete a 2-page questionnaire on IBD-related research, including rating the importance of 10 proposed research topics on a scale of 1 to 10.

RESULTS

52 patients completed the questionnaire, mostly females (54%) with Crohn's disease (54%) with 50% aged less than 20 (**Table 1**).

All 10 proposed research topics were rated of high importance, ranging from a mean rating of 8.1/10 for research into endoscopy in IBD while developing safe and more effective drugs was rated most important with a mean rating of 9.4/10 (**Fig. 1**).

60% had previously participated in research while 93% were interested in taking part in a future study. (**Fig. 2**). Travel distance and time commitment were the main barriers to participating in research. 94.2% were happy for their blood and biopsy samples to be used for research with 90% happy for their medical records to be used. However, 67% wished to be contacted for permission each time their medical records were used (**Fig. 3**).

Table 1. Patient demographics	
Total n	52
Female	28 (53.8%)
Age*	
<20 yo	25 (50%)
20-40 yo	17 (34%)
40-60 yo	8 (16%)
>60 yo	0
Phenotype**	
UC	22 (43.1%)
Crohn's	28 (54.9%)
Unsure	1 (2%)

*2 responses not recorded. **1 response not recorded.

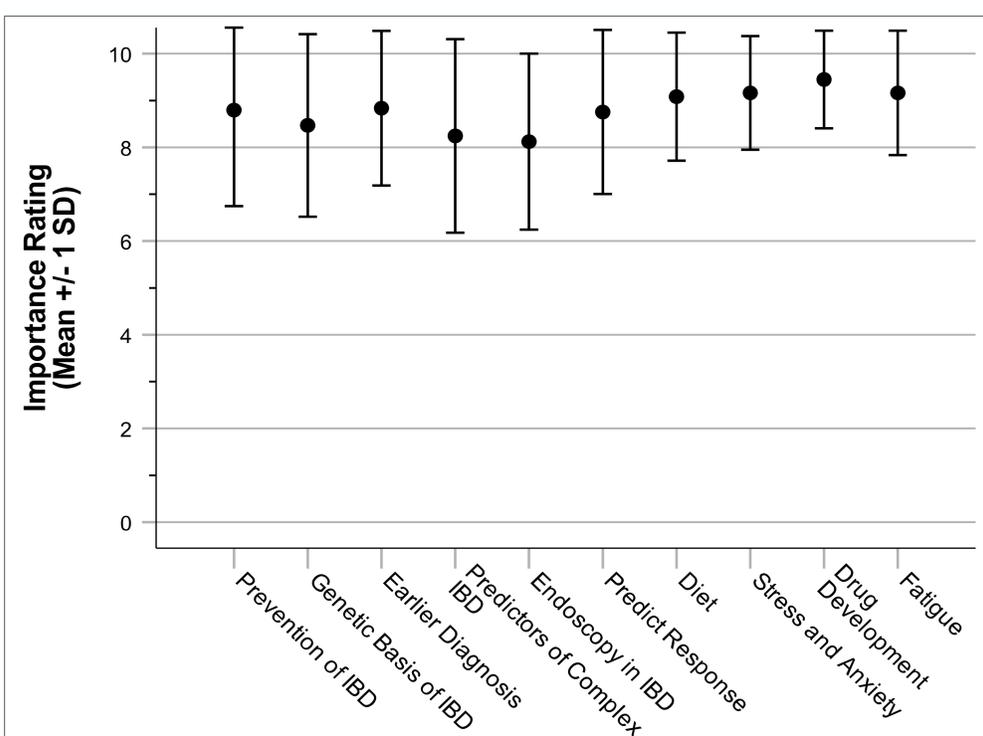


Figure 1. Patients' importance rating of proposed research topics

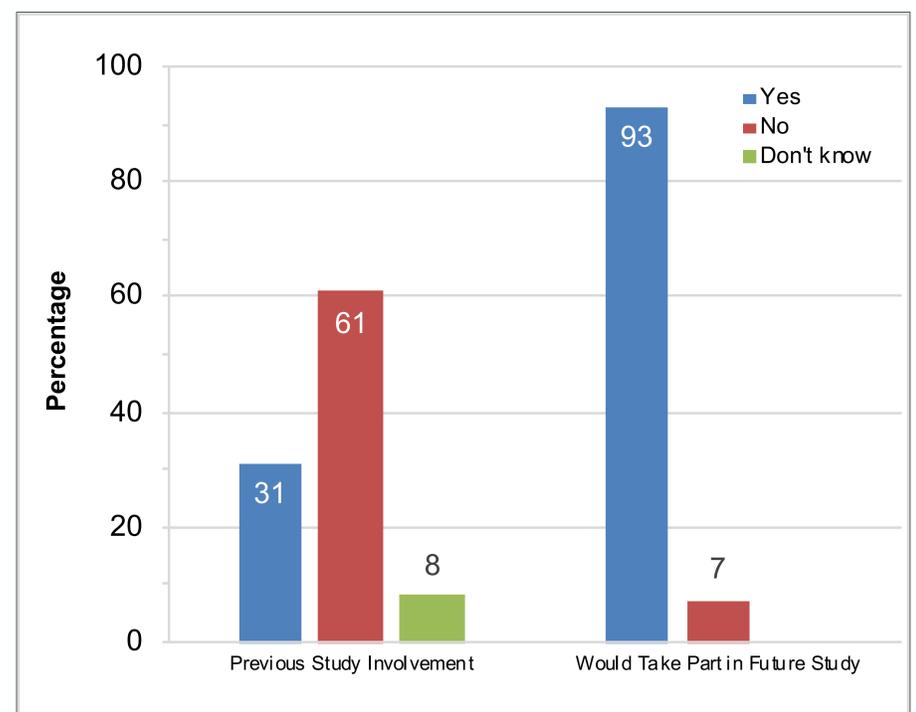


Figure 2. Patients' history of study participation and interest in future study.

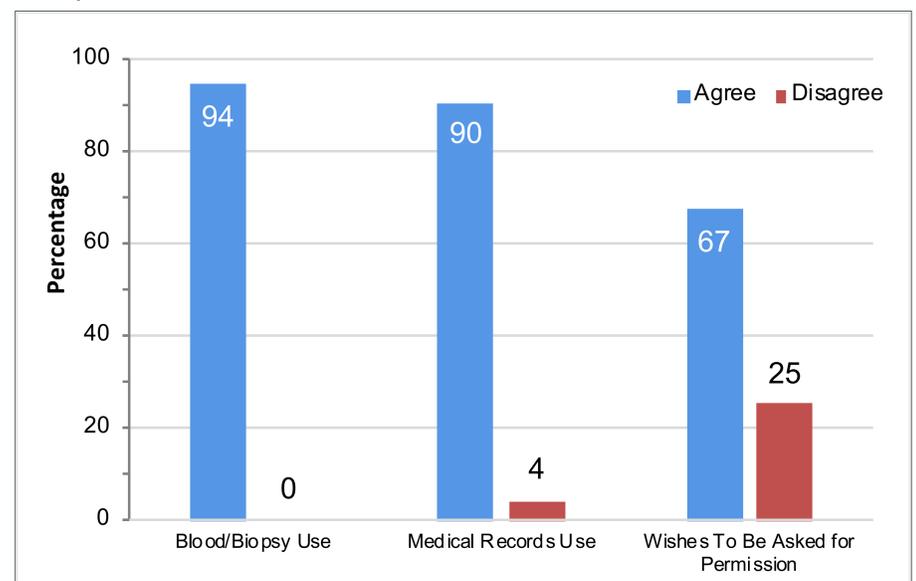


Figure 3. Patient's attitudes towards personal data use for research.

CONCLUSION

Patients living with IBD feel the development of more effective drugs is the most important research area. The majority have previously participated in research while over 90% would do so in the future. Most are also happy for their samples and medical records to be used, but two-thirds wish to be contacted for permission.

The results of this study will help to inform future research priorities of the INITIative network.

ACKNOWLEDGEMENTS

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