


BRIEF COMMUNICATION

Development of inflammatory bowel disease patient education and medical information sheets: serving an unmet need

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inflammatory bowel disease, patient, resources, education.

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Abstract

Inflammatory bowel disease is a chronic gastrointestinal condition that necessitates life-long healthcare engagement and management. Empowering patients with knowledge is fundamental to enhance health literacy, improve health outcomes and facilitate complex decision-making regarding medication and potential surgery. A working group was formed to develop concise, comprehensive patient information sheets to meet this unmet need in the Australian setting.

Inflammatory bowel disease (IBD) is a life-long condition that may cause multiple gastrointestinal and systemic symptoms, with significant impairment in quality of life. It is estimated that more than 100 000 Australians suffer from IBD.¹ Patients with IBD require numerous and repeated episodes of contact with the healthcare system and professionals. Given the wide-ranging effects of IBD on quality of life, comprehensive multidisciplinary

consultations are required, detailing discussions around therapeutic choices, surgical options, and psychological wellbeing and lifestyle to achieve optimal outcomes. Effective, sustained communication by providers is essential to empower, engage and guide patients through the complex decision-making processes. Unsurprisingly, patients have identified a desire for greater input into their medical care.² Despite this, there are limited Australian-based resources for patients with this chronic gastrointestinal disorder, being restricted to pharmaceutical-branded resources with potential for perception of bias. Provision of information to patients has thus been identified as a priority area in the IBD National Action Plan.³ Consequently, this was identified as a necessity by the Gastroenterological Society of Australia (GESA), and a multidisciplinary working group was established for creation of written evidence-based information resources for patients.

Health literacy, defined as the ‘combination of personal competencies and situational resources needed for people to access, understand, appraise and use information services’⁴ is needed to make health decisions. Limited health literacy in patients with IBD has been associated with depression, greater clinical disease activity, and overall worsened health status and health-related quality of life.^{5,6} Enhancing health literacy may subsequently lead to improved healthcare outcomes

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through improving self-efficacy, promoting timely and effective healthcare utilisation and prevention services.⁷ This may, in turn, reduce healthcare burden,⁸ since higher health literacy is associated with improved use of preventative healthcare and screening behaviours such as vaccination and colon cancer screening.^{6,9,10} The natural history of IBD entails periods of remission and flares, with patients at risk of hospitalisation, surgery and increased cancer risk. Combined with the multi-dimensional nature of care encompassing invasive endoscopic examinations, imaging, regular blood and stool tests, immunomodulatory and biologic therapies, the need for effective and sustained engagement of patients is paramount. Individual patient education in IBD has been shown to enhance insight, rationale and adherence to medical therapy, ultimately increasing patient satisfaction and reducing outpatient visitation and healthcare costs.^{11–13} Previous studies have highlighted medical specialists, family doctors, brochures and booklets, and recommended websites to be acceptable and effective sources of information according to patients with IBD.^{14,15} Lack of patient educational programmes and materials can result in seeking of information from uncontrolled and biased sources,¹⁶ hence a unified and evidence-based approach to patient education is essential in optimising IBD patient management.¹⁶

Patient education is hallmarked by the transfer of knowledge and skills to enable behavioural change, and includes assistance with facilitating informed health decisions.^{17,18} A decision aid is an evidence-based tool created to assist patients in making considered healthcare choices and is used to supplement clinicians' advice rather than replace it.¹⁹ Decision aids are distinguished from routine health education information through their tailored and individualised content, focussing on choices and outcomes resultant from decision-making.¹⁹ Implementation of decision aids in patient care reduces conflict and the feeling of being uninformed compared to standard care.¹⁹

Evidence-based patient information (EBPI) is essential for informed decision-making, with decision aids demonstrably improving decision quality.^{18,19} Typically, EBPI should include the purpose regarding any intervention, alternative options, uncertainties regarding diagnosis and prognosis as well potential risks and benefits and probability of therapeutic success or failures and side-effects.¹⁸ Numerical representation of data, diagrams, and graphics should supplement verbal information where possible.¹⁸ Importantly, plain language is critical for readability and should be preferentially used to simply, logically and clearly explain information with avoidance of complex or gender-specific terminology,¹⁸ recognising that material immersed with medical jargon

is unsuitable, especially for those with pre-existing low health literacy.²⁰ As proficiency of language is key in the comprehension of information, translation into other language formats is advisable to foster for broader audiences, as is avoidance of an alarmist or patronising tone.¹⁸ Involvement of consumers throughout the development stage is beneficial to assist in striking this balance.¹⁸

Recognising the relative paucity of dedicated Australian-based information materials for patients with IBD, a working group was formed with endorsement by GESA and its IBD Faculty Executive Committee with the aim of developing comprehensive evidence-based, trustworthy, unbiased and user-friendly resources. The IBD Patient Information Materials Working Group comprised a multidisciplinary team of eight adult and one paediatric gastroenterologist, two colorectal surgeons, three clinical nurse consultants, three pharmacists, three dietitians, three psychologists, a stoma therapist, an expert in health educational linguistics, and three consumer representatives (Table 1). A series of 90–120-min online meetings were held commencing in October 2020, with the identification of patient information materials of need and proposed structure of each information sheet discussed in the first meeting, followed by drafting and revision of sheets over the subsequent six meetings. Further drafting was undertaken offline between meetings and following the last meeting held in July 2021 to achieve consensus.

Information sheets pertaining to general information about Crohn disease, ulcerative colitis, and pregnancy and IBD, were already present on the GESA website, having been developed within the previous 2 years (Table 2). These were not revised as part of this project. The topics selected for creating and revision regarded: diet; travel; vaccinations; sexual health; mental health; surgery; and life with a stoma. Information sheets

Table 1 Working group members

Specialty type	Number involved
Adult gastroenterologists	8
Paediatric gastroenterologist	1
Colorectal surgeons	2
Gastroenterology advanced trainees	1
IBD clinical nurse consultants	3
Stoma therapy nurse	1
IBD pharmacists	3
Gastrointestinal dietitian	3
Specialist gastrointestinal psychologists	3
Consumer representatives	3
Educational linguist	1

IBD, inflammatory bowel disease.

Table 2 Information sheet topics

Topic	
General	Travel and IBD
	Vaccinations and IBD
	Mental Health and IBD
	Sexual Health and IBD
	Diet and IBD
	Surgery and IBD
	Life with a Stoma
	Complementary and Alternative Therapies
Medications	5ASA
	Corticosteroids
	Thiopurines
	Methotrexate
	Infliximab
	Adalimumab
	Golimumab
	Ustekinumab
	Vedolizumab
	Tofacitinib

IBD, inflammatory bowel disease.

covering all currently available pharmaceutical agents were also created, including: 5ASA; thiopurines; methotrexate; infliximab; adalimumab; vedolizumab; ustekinumab; and tofacitinib. The Evaluative Linguistic Framework was used to guide balance of medical and lay language whilst also aiming to keep sheet length within two to four pages maximum. Topics were distributed among select authors, pertaining to their area of expertise to create the initial drafts. The draft documents were then uploaded onto a shared electronic drive with further information, edits, and contributions sought from

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the wider group. Following drafting by the working group, these information sheets were provided to the GESA board for final approval.

The resources are now available online on the GESA website (<https://www.gesa.org.au/education/patient-resources/>) and are readily available to clinicians within the field for easy access during consultations, as well as being freely available to the public through both the GESA and Crohn's and Colitis Australia (CCA) websites.

Discussion

IBD results in a significant impact in the quality of life for over 100 000 people in Australia. Given limitations for face-to-face interactions placed by the COVID-19 pandemic, the need for tools to supplement consultations takes on greater importance. The development of a wide range of dedicated patient information materials by the GESA Working Group aims to address an unmet need for patients, their families and clinicians in Australia, consequently leading to empowerment and engagement of patients with their healthcare providers.

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