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**REVIEW ARTICLE** 

# Improving quality of care in inflammatory bowel disease: What changes can be made today?



Julián Panés<sup>a,\*</sup>, Marian O'Connor<sup>b</sup>, Laurent Peyrin-Biroulet<sup>c</sup>, Peter Irving<sup>d</sup>, Joel Petersson<sup>e</sup>, Jean-Frédéric Colombel<sup>f</sup>

- <sup>a</sup> Hospital Clinic University of Barcelona, IDIBAPS, CIBERehd, Barcelona, Spain
- <sup>b</sup> St Mark's Hospital, Harrow, United Kingdom
- <sup>c</sup> INSERM Unité 954 and Department of Gastroenterology, University of Lorraine, Nancy, France
- <sup>d</sup> Department of Gastroenterology, Guy's and St Thomas' Hospital, London, United Kingdom
- <sup>e</sup> Global Medical Affairs Gastroenterology, AbbVie, Rungis, France

Received 26 November 2013; received in revised form 25 February 2014; accepted 26 February 2014

### **KEYWORDS**

Inflammatory bowel diseases; Crohn disease; Ulcerative colitis; IBD centres of excellence; Multidisciplinary team; Quality of care

#### **Abstract**

*Background and aims*: There are a number of gaps in our current quality of care for patients with inflammatory bowel diseases. This review proposes changes that could be made now to improve inflammatory bowel disease care.

Methods: Evidence from the literature and clinical experience are presented that illustrate best practice for improving current quality of care of patients with inflammatory bowel diseases. Results: Best care for inflammatory bowel disease patients will involve services provided by a multidisciplinary team, ideally delivered at a centre of excellence and founded on current guidelines. Dedicated telephone support lines, virtual clinics and networking may also provide models through which to deliver high-quality, expert integrated patient care. Improved physician—patient collaboration may improve treatment adherence, producing tangible improvements in disease outcomes, and may also allow patients to better understand the benefits and risks of a disease management plan. Coaching programmes and tools that improve patient self-management and empowerment are likely to be supported by payers if these can be shown to reduce long-term disability.

E-mail address: jpanes@clinic.cat (J. Panés).

f Department of Gastroenterology, Mount Sinai School of Medicine, New York, NY, USA

Abbreviations: CRP, C-reactive protein; HCP, healthcare professional; IMID, immune-mediated inflammatory diseases; MDT, multidisciplinary team.

<sup>☆</sup> This manuscript summarises the presentations made during the 'Leading Change in IBD' meeting held in Madrid on 18–19 January 2013 and sponsored by AbbVie.

<sup>\*</sup> Corresponding author at: Department of Gastroenterology, Hospital Clinic of Barcelona, Villarroel 170, 08036 Barcelona, Spain. Tel.: +34 93 2275418; fax: +34 93 2279387.

920 J. Panés et al.

Conclusions: Halting disease progression before there is widespread bowel damage and disability are ideal goals of inflammatory bowel disease management. Improving patient—physician communication and supporting patients in their understanding of the evidence base are vital for ensuring patient commitment and involvement in the long-term management of their condition. Furthermore, there is a need to create more centres of excellence and to develop inflammatory bowel disease networks to ensure a consistent level of care across different settings.

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#### **Contents**

1. An introductory overview: what can we do better?
1.1. Earlier diagnosis, earlier intervention and better adherence to guidelines
1.2. Preventing long-term disease progression
2. What do we do well and what difference has it made?
3. Fostering physician—patient collaboration
4. Communicating benefit/risk to patients
5. Working within the healthcare system to improve care
6. The future — what needs to be done
Conflict of interest
Acknowledgements
References

# 1. An introductory overview: what can we do better?

Inflammatory bowel diseases (IBDs) are emerging as a worldwide epidemic, with prevalence of around 1% in North America and some European countries, and a rapid increase in incidence reported in Asia, China and Australasia. A number of recent reports and publications point to the burden that this rising tide of IBD is imposing on patients, healthcare services and society. For example, a comprehensive and large-scale study in Denmark comparing ulcerative colitis (UC) and Crohn's disease (CD) patients with matched controls has shown that a diagnosis of IBD increases both immediate- and long-term risk of mortality. Furthermore, patients with IBD are more likely to be in receipt of disability allowances than age-matched individuals from the general population, reflecting the impact of an IBD diagnosis on health-related quality of life and productivity.

# 1.1. Earlier diagnosis, earlier intervention and better adherence to guidelines

The IMPACT patient survey, conducted in 27 European countries and sampling responses from almost 5000 IBD patients (63% CD, 33% UC), highlights a number of gaps in current clinical care. Overall, 18% of IBD patients reported that they waited over for 5 years before receiving a diagnosis, and 67% needed emergency care before receiving a diagnosis. Moreover, 53% reported they felt unable to tell their doctor something important at a consultation. Other evidence that suggests that there is room for improvement in the current care of patients with IBD comes from a recent

survey of IBD patients in France.<sup>5</sup> This questionnaire-based study found that, contrary to current guideline recommendations, only around 30% of patients with long-standing extensive colitis received a screening colonoscopy. Furthermore, a US physician survey reported that 29% of physicians were unaware of guidelines recommending venous thromboembolism prophylaxis in hospitalised IBD patients and that only 35% would provide pharmacological prophylaxis to hospitalised patients with severe UC.<sup>6</sup> There is also evidence from population-based studies that many patients are still treated late in the course of their disease, even with current-day treatment algorithms founded on earlier use of immunosuppressants and biological therapy. One of the issues that complicate quality of care is the plethora of guidelines available from a number of professional societies, covering a range of specific scenarios. At least some of these may be rapidly outdated and may be difficult to locate or follow, particularly by non-IBD specialists.

#### 1.2. Preventing long-term disease progression

There is a need for wider appreciation of the progressive nature of IBD and the importance of early diagnosis and intervention at earlier stages of disease, ideally before disease progression occurs. <sup>8,9</sup> In CD, there is progressive digestive damage in addition to the characteristic episodes of inflammatory activity, with a growing body of evidence showing that this condition needs to be viewed not simply as series of intermittent flares but as a disease with a continuous pathology<sup>9</sup> (Fig. 1). There are also emerging data to suggest that mucosal healing in CD and UC patients is associated with a reduction in the need for subsequent surgical resection over the following decade. <sup>10</sup> The role of

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