INTRODUCTION

To deliver quality care for IBD, increasing sophistication, coordination and collaboration is required as therapeutic options and monitoring techniques increase. Indeed, improvements in quality of care are essential to meet the needs and expectations of the growing population of patients with IBD. Although there is evidence of improving care for IBD as a whole, variability and inconsistency in management persist, both within and between regions and countries.

IBD2020 global forum: results of an international patient survey on quality of care

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Background/Aims: IBD2020 is a global forum for standards of care in inflammatory bowel disease (IBD). The aim of the IBD2020 survey was to identify and describe variations in quality care of IBD. Methods: Patients with IBD from Finland, Italy, France, Canada, Germany, UK, Spain and Sweden were surveyed during 2013 to 2014, covering: disease characteristics; impact on life and work; organization and perceived quality of care. Results: Seven thousand five hundred and seven patients participated (median age, 39 years [range, 10–103 years]; 2,354 male [31.4%]), including 4,097 (54.6%) with Crohn’s disease (CD) and 3,410 (45.4%) with ulcerative colitis (UC). Median time from symptom onset to diagnosis was 1 year for both CD (range, 0–47 years) and UC (range, 0–46 years), with no clear evidence of improvement in diagnostic delay over the preceding 24 years. Half of the patients (3,429; 50.0%) rated their care as “excellent” or “very good,” with similar results for CD and UC across countries. Five factors were significantly (P<0.01) associated with perceived good quality of care: quality of specialist communication; review consultation being long enough; failure to share information; no access to a dietician; speed of advice. Conclusions: The IBD2020 survey has highlighted areas related to quality of care of IBD from the patients’ perspective, with scope for improvement. (Intest Res 2018;16:537-545)

Key Words: Inflammatory bowel disease; Crohn disease; Colitis, ulcerative; Surveys and questionnaires; Quality of health care
METHODS

1. Survey Design
The IBD2020 survey (June 2013–June 2014) consisted of 67 core questions designed to capture patient perspectives on quality of care related to: (1) disease characteristics (diagnosis, severity of condition, current medication); (2) effect on work and life; (3) organization of care; (4) information provision and access to a multidisciplinary team (MDT); or (5) perception of quality of care (overall, communication, coordination).

The questionnaire was designed by Richard Driscoll (then co-chair of IBD2020, former CEO Crohn’s & Colitis UK), based on previous questionnaires to Crohn’s & Colitis UK members and other patient-based questionnaires. All questions were closed with multiple choice answers. The English questionnaire (Supplementary Material 1) was piloted for plain language and comprehensibility among 10 patient-volunteers. Patients from 8 countries (Canada, Finland, France, Germany, Italy, Spain, Sweden, and UK) were invited to participate, which was carried out in association with respective national patient associations. The questionnaire was available online, translated into native languages by the patient associations, with invitations sent via email, Facebook, or letter.

2. Statistical Analysis
Questionnaires with missing data relating to diagnosis and/or with ≥95% overall missing data were excluded from analyses. Answers were summarized based on the total number of respondents to each question, with those patients missing data for a question excluded from that particular analysis. Reported rates of unemployment were compared against national averages for June 2014. A primary diagnosis of any form of colitis was grouped under UC, irrespective of whether CD was also reported. The reliability of the questionnaire was tested by calculation of Cronbach’s coefficient for the sections of the questionnaire dealing directly with the respondents’ assessment of the quality of service provision was 0.69, indicating relatively good reliability.

Over half (3,664/6,178 [excluding Canada], 59.3%) of the respondents were members of a patient organization, with respondents from Finland most likely to give an affirmative answer (1,091/1,207, 90.4%) and those from the United Kingdom being least likely (302/850, 35.5%).

2. Disease Characteristics
Median time to diagnosis from first seeking medical care for symptoms was 1 year for both CD (range, 0–47 years) and UC (range, 0–46 years) and, assessed by date of diagnosis, was similar over the past 24 years (P=0.319) (Fig. 1). However, when analyzed based on onset of symptoms, rather than date of diagnosis, there was a significant improvement in mean time to diagnosis for both CD and UC with advancing
Table 1. Demographics: Overall and Divided by Country of Respondent

|                         | Overall | Canada  | Finland | Italy   | France  | Germany | UK    | Spain  | Sweden |
|-------------------------|---------|---------|---------|---------|---------|---------|-------|--------|--------|
| No. of patients         | 7,507   | 1,308   | 1,212   | 1,064   | 929     | 887     | 851   | 661    | 595    |
| Age (yr)                | 39 (14–103) | 45 (14–103) | 40 (14–80) | 39 (14–79) | 36 (14–79) | 35 (14–103) | 36 (14–72) | 49 (14–81) |
| Sex                     |         |         |         |         |         |         |       |        |        |
| Male                    | 2,354 (31.4) | 398 (30.5) | 349 (28.8) | 448 (42.2) | 252 (27.2) | 244 (27.5) | 210 (24.8) | 247 (37.4) | 206 (34.7) |
| Female                  | 5,140 (68.6) | 907 (69.5) | 861 (71.2) | 613 (57.8) | 676 (72.8) | 643 (72.5) | 638 (75.2) | 414 (62.6) | 338 (65.3) |
| Diagnosis               |         |         |         |         |         |         |       |        |        |
| CD                      | 4,097 (54.6) | 785 (60.0) | 394 (32.5) | 584 (54.9) | 592 (63.7) | 536 (60.4) | 501 (58.9) | 401 (60.7) | 304 (51.1) |
| UC<sup>a</sup>          | 3,410 (45.4) | 523 (40.0) | 818 (67.5) | 480 (45.1) | 337 (36.3) | 351 (39.6) | 350 (41.1) | 260 (39.3) | 291 (48.9) |
| Disease duration (yr)   | 8 (0–60) | 11 (0–60) | 7 (0–46) | 9 (0–48) | 8 (0–45) | 5 (0–55) | 7 (0–42) | 13 (0–57) |
| Highest level of education |       |         |         |         |         |         |       |        |        |
| Primary                 | 929 (12.4) | 25 (19)  | 113 (9.4) | 166 (15.7) | 29 (3.1) | 456 (51.6) | 14 (1.7) | 57 (8.6) | 69 (11.6) |
| Secondary               | 3,075 (41.2) | 286 (21.9) | 726 (60.1) | 557 (52.8) | 364 (39.5) | 200 (22.7) | 440 (51.9) | 268 (40.6) | 234 (39.4) |
| University              | 3,468 (46.4) | 994 (76.2) | 368 (30.5) | 332 (31.5) | 528 (57.3) | 227 (25.7) | 393 (46.4) | 335 (50.8) | 291 (49.0) |
| Current smoker          | 1,227 (16.4) | 127 (9.7)  | 161 (13.3) | 240 (22.6) | 200 (21.6) | 183 (20.6) | 124 (14.6) | 147 (22.3) | 45 (7.6)  |
| Member of patient organization | 3,664 (59.3)<sup>b</sup> | 1,081 (90.4) | 537 (50.7) | 418 (45.2) | 487 (56.3) | 302 (35.5) | 299 (45.4) | 520 (87.4) |

<sup>a</sup>Values are presented as median (range) or number (%). All values were calculated based on the total number of respondents to that question with missing data excluded.

<sup>b</sup>IBD unclassified was included with UC.

<sup>c</sup>Number of patients asked (% of total).

<sup>d</sup>Patients from Canada were not asked this question.

<sup>e</sup>Patients from Canada were not asked this question.
time (both \(P=0.001\)) (Supplementary Table 2). More than half of the patients (4,221; 56.7%) sought emergency care prior to diagnosis, with 917 (12.3%) visiting an emergency department 5 or more times before diagnosis. Approximately one-third (2,542; 34.0%) of patients had undergone gastrointestinal surgery, of whom 1,997 (48.9%) had CD and 545 (16.1%) UC (\(P=0.001\)). In total, 1,010 patients (39.8%) required a stoma following surgery (CD: 580 [29.1%] vs. UC: 430 [78.9%]; \(P<0.001\)), with half (514; 50.9%) still having a stoma at the time of the survey (CD: 317 [54.7%] vs. UC: 197 [45.8%]; \(P=0.001\)).

Fewer than a quarter (1,748; 23.7%) of respondents described their disease as being in remission in the previous 3 months, with 1,646 (22.3%) describing more than 5 flares or continuous activity in the preceding year. As a result, 2,038 patients (27.7%) had been admitted to hospital over the course of that year. In the preceding 2 years, 1,828 patients with CD (47.1%) and 1,612 with UC (51.5%) had received steroids (\(P=0.001\)), with 1,969 (57.4%) patients taking steroids for longer than 3 months as a single course (Supplementary Fig. 1). More patients with CD than UC were taking anti-depressants (17.5% [597] vs. 14.7% [422], respectively; \(P=0.004\)) and analgesics (31.8% [1,084] vs. 21.3% [604]; \(P<0.001\)).

### 3. Effect of Disease on Work and Life

Inability to work due to IBD obliged 638 patients (8.5%) either to retire early or go on long-term sick leave. Unemployment rates for those with IBD were higher than contemporaneous national averages in 2 of the 8 countries (Italy: 15.7% vs. 12.1%, respectively, \(P<0.01\); and Germany: 5.7% vs. 5.0%, \(P=0.450\)) (Supplementary Fig. 2). For those in work or studying (5,080), 2,906 (57.2%) reported that they had to take time off due to their disease in the preceding 12 months, with a higher rate for those with CD (1,622/2,694; 60.2%) than UC (1,284/2,386; 53.8%; \(P=0.001\)). The median number of days missed for all respondents was 2 (range, 0–25), while for those who reported absenteeism it was 8 (range, 1–25), and IBD-related symptoms prevented 4,935 patients (69.0%) from undertaking normal activities for 18 days (range, 1–25) in the preceding year. Over half of patients in the United Kingdom and Germany (1,738) reported that their symptoms resulted in significant fatigue more than half of the time (1,196; 69.4%), significant pain (994; 58.7%), nocturnal waking (938; 54.9%), or anxiety or depression (910; 53.5%).

### 4. Organization of Care

Around three-quarters (4,589; 74.0%) of respondents normally consulted a gastroenterologist about their care. Of the remainder, 502 (8.1%) consulted a primary care physician, 442 (7.1%) a specialist nurse, 396 (6.4%) a surgeon, and 274 (4.4%) a non-gastroenterology hospital physician. Whilst a gastroenterologist was the primary point of care in all countries, there was considerable variation, ranging from 50.4% (404/802) of patients in the United Kingdom compared to 91.9% (799/869) in France (Fig. 2). Care was most often received in a general hospital (3,089; 49.8%), followed by university hospital (1,603; 25.9%), local surgery/healthcare clinic (833; 13.4%), and private clinic or hospital (673; 10.9%).

Contact with their healthcare provider (IBD professional) was more commonly through regular review (3,073; 53.3%) than ad hoc telephone calls (2,307; 40.0%) or e-mail (384; 6.7%). Most reviews were carried out face-to-face (3,398; 89.7%), with only 623 (10.3%) having their last review over the telephone, via email, or postal questionnaire. Nearly a quarter (1,405; 23.4%) of respondents felt that their last review was not long enough, with 3,529 (58.6%) having a review lasting 15 minutes or less. Some patients (990; 14.1%) did not have a regular review organized, with nearly half of these (441; 45.9%) feeling that this was unacceptable. Nearly three-quarters (4,858; 73.0%) of respondents who were not already doing so indicated that they would like to communicate to their doctor or nurse through online chat. Overall, over half of patients (3,737; 56.3%) responded that they felt the healthcare system in their country needs to be much better at using modern information technology.

In the event of a disease flare, patients generally sought advice from their usual provider of care (Spearman correlation test, \(P=0.001\)) (Supplementary Table 3). For those not in work or studying (4,051), 1,057 (26%) reported that their disease or the care they received prevented them from doing their job for 12 months or more, with a higher rate for those with CD (617/1,293; 47.7%) than UC (440/1,262; 34.7%; \(P=0.001\)). The median number of days missed for all respondents was 12 (range, 0–125), while for those who reported absenteeism it was 40 (range, 0–125), and IBD-related symptoms prevented 4,935 patients (69.0%) from undertaking normal activities for 18 days (range, 1–25) in the preceding year. Over half of patients in the United Kingdom and Germany (1,738) reported that their symptoms resulted in significant fatigue more than half of the time (1,196; 69.4%), significant pain (994; 58.7%), nocturnal waking (938; 54.9%), or anxiety or depression (910; 53.5%).

### Fig. 1. Period of time between first seeking medical care for symptoms and confirmed diagnosis (n=7,507). \(P=0.319\) for difference in time to diagnosis over study period (Kruskal-Wallis H test).
A quarter of respondents (1,610; 24.6%) had to wait 4 or more days to receive this advice. Advice provided by email or telephone was significantly quicker than face-to-face advice (P<0.001 in either case). A second opinion about their IBD had been sought by 1,102 patients (17.4%) within the preceding year.

When admitted to hospital, almost half the patients (2,040; 41.5%) were not on a specialist gastroenterology ward. Irrespective of admission to a specialist or non-specialist ward, about a third of respondents (1,745; 35.5%) felt that there were too few toilets available.

5. Information Provision and Access to Multidisciplinary Team

Approximately a quarter of patients (excluding those who could not remember) had not had a discussion about the basic characteristics of IBD (1,743; 24.4%) or about treatment goals (1,930; 27.4%) within 3 months of diagnosis (Fig. 3). Approaching half (2,848; 40.5%) had not discussed the benefits or risks of treatment options. The impact of smoking was discussed with only 2,623 (37.4%) of respondents (CD, 1,909 [49.4%]; UC, 714 [22.7%]; P=0.001). A quarter of respondents (1,610; 24.6%) had social workers (837; 13.0%), counsellors (323; 6.1%), or social workers (302; 4.8%), with significant differences between countries (P<0.001 in either case). A second opinion about colorectal surgeon (2,178; 32.8%), dieticians (1,358; 20.8%), psychologists (837; 13.0%), counsellors (323; 6.1%), or social workers (302; 4.8%), with significant differences between countries (P<0.001 in all except rheumatologist [P=0.022] or social worker [P=0.720] (Fig. 4). Of those who did not have access to a particular professional, many felt they had an unmet need: dieticians (2,449; 47.5%), psychologists (1,851; 33.1%), counsellors (1,535; 30.7%), clinical nurse specialists (1,127; 25.3%), social workers (919; 15.4%). A higher proportion of male than female respondents indicated access as not needed for 6 of 8 types of healthcare professional (all P<0.05), but the former indicated a higher unmet need for access to a colorectal surgeon (P<0.001) (Supplementary Table 3).

6. Perception of Quality of Care

Half (3,429; 50.0%) of the respondents rated their care as excellent or very good, with only 358 patients (5.2%) considering their care poorly coordinated (Fig. 5). Similar patterns were seen for CD and UC (“excellent” and “very good” vs. “fair” and “poor”).
Five factors were significantly associated with perceived excellent or very good quality of care: (1) quality of specialist communication (excellent: OR 128.9, \( P < 0.001 \); very good: OR 41.7, \( P < 0.001 \); good: OR 6.6, \( P < 0.001 \)); (2) whether the review consultation was long enough (yes: OR 1.8, \( P < 0.001 \)); (3) failure to share information in the past 2 years (no: OR 1.7, \( P < 0.001 \); yes: OR 0.7, \( P = 0.038 \)); (4) no access to a dietician (OR 0.7, \( P = 0.003 \)); and (5) speed of advice in case of flare (same day: OR 1.6, \( P = 0.006 \)). The 5 factors were rated similarly by both sexes, though quality and speed of communication appeared more important to females, whilst failure to share information and access to a dietician appeared more important to men (Supplementary Table 4). Factors not significantly associated with quality of care included: frequency of regular review; coordination of care; how advice received in the event of a flare; access to MDT; primary/main healthcare professional consulted; usual place of care.

DISCUSSION

The IBD2020 survey included over 7,500 patients from 8 countries and provides insights into delivery of care, perceived quality of care and areas for improvement. Overall, half the respondents rated their care as excellent or very good, with similar results reported for those with CD or UC and between countries. The most important driver of quality of care identified from the patients’ perspective was communication with their healthcare provider (\( P < 0.001 \)). Disappointingly, only half the patients (50.9%) described communication as excellent or very good.

Poor communication included insufficient discussion about fundamental aspects of patients’ care within 3 months of diagnosis, including characteristics of IBD (24.4%), treatment goals (27.4%), or risks-benefits of treatment (40.5%). Half the patients with CD (50.6%) could not recall being told about the importance of avoiding smoking, despite well-established risks associated with smoking and exacerbation of CD. For patients with established disease, communication deficits in the preceding 12 months included insufficient discussion of the goals of treatment (48.1%), general lifestyle issues (44.8%), medical treatment options (16.2%), or current symptoms (11.8%). Inadequate sharing of information between healthcare professionals was reported by nearly a quarter of the patients (22.4%, \( P < 0.001 \)). Dissatisfaction with patient-provider communication has been reported in other patient surveys. In the IMPACT survey of 4,670 patients with IBD from 25 European countries, 64% of respondents believed that their gastroenterologist should have asked more probing questions to understand their disease. A similar response (68.6%) to the same question was found when the IMPACT survey was repeated in 172 Japanese patients with IBD. Similarly, in survey by the European Federation of Crohn’s and Ulcerative Colitis Associations (EFC-CA), 47.8% of 5,576 patients with IBD reported that their physician did not ask about the impact of symptoms on their quality of life. Improved healthcare professional-patient communication
through awareness, education and training should facilitate patients’ understanding of the benefits and risks of treatment, potentially leading to increased adherence and better disease outcomes. Most communication was by planned, face-to-face reviews (53.3% of contacts were reviews of which 89.7% were face-to-face), but almost a quarter of patients (23.4%) felt that their last review was not long enough (58.6% ≤15 minutes; P<0.001). Speed of advice in event of a flare was identified as a key driver of good quality of care (P<0.006). Inadequate access to their IBD professional has been identified as an area for improvement in other European surveys, but not in the Japanese IMPACT survey, where 79.1% felt access was adequate. It may be unrealistic to expect face-to-face consultations in busy clinics to be extended, but improved access through telephone or email could help. Our survey confirms that advice by telephone or email was significantly faster than face-to-face consultation (both P<0.001).

Empowering and encouraging patients to be more forthcoming during consultations with healthcare providers (e.g., through the use of coaching programmes) represents another strategy to improve communication. The IBD2020 survey indicates that respondents felt a high level of involvement in decisions about their treatment (always/nearly always: 72.9%), including the ability to ask important questions (81.3%). In the IMPACT surveys, however, half (Europe, 54%; Japan, 45.9%) the respondents had not felt able to tell their physician something important about their illness, while 44.1% of patients in the EFCCA survey were not prepared to initiate discussions with their physician on the impact of symptoms on their quality of life. Nevertheless, once a patient had raised such questions with their physician, most (79.6%) felt that action would be taken.

Access to multidisciplinary care, a central tenet of IBD quality standards, varied considerably across countries, given differences in healthcare systems. Interestingly, the speciality associated with good quality of care other than the lead IBD professional (a gastroenterologist in 74.0%) was access to a dietician (P=0.003). Yet overall, 20.8% of patients had access to a dietician (ranging from 40.6% in Sweden to 10.0% in Italy), whilst 47.5% of those who did not have access felt the need for such contact. A third of respondents also wanted access to psychologists (33.1%) or counsellors (30.7%), suggesting that for these patients, emotional needs were not being addressed adequately, which, in turn, affected their perception of quality of care. Two-thirds of respondents (67.2%) did not have access to a clinical nurse specialist, though, perhaps surprisingly, only a quarter of these patients (25.3%) felt that they had the need. This suggests that patients consider the nurses’ role to be mostly clinical, supporting that of the gastroenterologist. It may be a case of “not knowing what you’re missing,” since the support that IBD specialist nurses provide is a well-recognized component of quality care. Nurse-led IBD helplines are an example of how patient-provider communication can be facilitated.

Despite increased awareness of IBD allied to a rising disease burden, there appeared to be no improvement in the time to diagnosis over the past 25 years. Many patients (56.7%) had to seek emergency care prior to diagnosis and at least 5 times in 12.3%. Similar results were reported in the IMPACT survey, where 45% of respondents received their final diagnosis after more than a year, 67% attending an emergency department prior to diagnosis and 7% more than 10 times. Delays in diagnosis of IBD have been reported in other surveys in Europe and Asia. More widespread use of fecal calprotectin alongside increased recognition of symptoms and “red flags” within primary and emergency care might facilitate referral of appropriate patients to IBD specialists.

There are several limitations to the IBD2020 survey. The open call to contribute via patient organizations will have introduced selection bias, apart from obviating a response rate. There was a preponderance of both female respondents (68.6%) and patients with CD (54.6%), as in the IMPACT surveys, suggesting that this is a common bias in questionnaire-based studies in IBD conducted in Europe. In contrast, patient surveys conducted in Asia appear to have the opposite bias in terms of gender (approximately two-thirds male respondents). The survey relied on patient recall, while the coarseness of some time intervals captured in the questionnaire are other inherent limitations. As is to be expected, representation was skewed towards patients with more severe disease who might have more motivation to participate. It should also be noted that none of these surveys have provided benchmarks for Quality of Care against which patients could gauge the care received.

Patient perception of quality of care in the IBD2020 survey was dominated by the quality of communication with the main healthcare provider, most often a gastroenterologist. Nevertheless, this is the single most important factor open to improvement. Rapid access to care, particularly during a potential flare, was also rated highly. Telephone advice lines and electronic media are practical ways of providing patients with reassurance that help and advice is readily available. In
terms of organization of care, access to a MDT was perceived by patients to be less important than access to specific specialties, in particular a dietician. Information from the IBD2020 survey provides a baseline of patient perception against which strategies aimed at quality improvement in IBD can be gauged.

FINANCIAL SUPPORT

IBD2020 has received support from AbbVie, Bühlmann, Enterome, Hive, StratX, KPMG, Health Soultions and Veryday.

CONFLICT OF INTEREST

No potential conflict of interest relevant to this article was reported.

AUTHOR CONTRIBUTION

S.P.L, P.I., J.B., R.D., and M.O. contributed to the concept and design of the study. R.D. organized the IBD2020 survey and J.R.F., J.B. and B.S.R-G. performed the analysis. All authors contributed to the manuscript.

ACKNOWLEDGEMENTS

We sadly acknowledge the untimely death of Richard Driscoll, one of the co-authors of this study and a Director of IBD2020 (UK Charity 1172495), who, through his work as CEO of Crohn’s and Colitis UK (formerly the National Association for Crohn’s and Colitis) and other projects, including Director of Development for the UK IBD Registry, made an enormous impact on the lives of patients with IBD.

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