Quality of Care in Inflammatory Bowel Disease: Actual Health Service Experiences Fall Short of the Standards

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Antonina Mikocka-Walus^{1*}, Associate Professor of Health Psychology

Wayne Massuger², Project Manager

Simon R. Knowles³, Senior Lecturer in Psychology

Gregory T. Moore^{4,5}, Associate Professor and Head of Inflammatory Bowel Diseases Unit

Stephanie Buckton⁶, IBD Nurse Practitioner

William Connell⁷, Consultant Gastroenterologist and Director of the IBD Multidisciplinary Service

Paul Pavli⁸, Professor of Gastroenterology and Gastroenterology & Hepatology Staff Specialist

Leanne Raven^{2,9}, Chief Executive Officer

Jane M. Andrews¹⁰, Professor of Gastroenterology and Head of Unit & Head IBD Service

¹ School of Psychology, Deakin University, Melbourne, Australia

² Crohn's & Colitis Australia, Melbourne, Australia

³ School of Health Sciences, Swinburne University of Technology, Melbourne, Australia

⁴ Department of Gastroenterology, Monash Medical Centre, Melbourne, Australia

⁵ School of Clinical Sciences, Monash University, Melbourne, Australia

⁶ Department of Gastroenterology, Sunshine Coast University Hospital, Birtinya, Australia

⁷ Department of Gastroenterology, St Vincent Hospital, Melbourne, Australia

⁸ Department of Gastroenterology, Canberra Hospital, Canberra, Australia

⁹ Faculty of Science, Health and Engineering, University of Sunshine Coast, Sippy Downs, Australia

¹⁰ IBD Service, Department of Gastroenterology and Hepatology, Royal Adelaide Hospital, Adelaide, Australia

***Corresponding author**
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School of Psychology, Deakin University, 221 Burwood Highway, Burwood, VIC 3128, Australia, Tel. 0061 3 92468575, Email: mikocka@deakin.edu.au

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Special thanks go to the more than 1000 people living with inflammatory bowel disease (IBD) who took the time to access this survey and provide important information for the improvement of the quality of care for those with IBD. Many contributed despite their health being affected by IBD at the time of survey.

This work was supported by unrestricted educational grants from Ferring Pharmaceuticals, Takeda Pharmaceuticals Australia and Janssen Australia and New Zealand awarded to Crohn's & Colitis Australia, a not-for-profit, patient support group. We do not have conflicts of interest in relation to the present study, however, here is the list of our COIs outside this work: AMW has served as an educational speaker for Janssen and Ferring. SRK has served as a consultant for AbbVie and Shire. GTM has served on the advisory boards for AbbVie, Emerge, Gilead, Hospira, Janssen, Orphan, MSD, Pfizer, Shire, Takeda. He received speaker's fees from AbbVie, Ferring, Janssen, Orphan, Roche, Shire, Takeda. He received research and educational support from AbbVie, Janssen, Shire, Takeda. SB has served on the advisory board Janssen and Abbvie, received education grants from Takeda, Shire, Janssen and Abbvie. JMA has served as a consultant for Abbott, AbbVie, Allergan, Anantara, AstraZeneca, Bayer, Celgene, Ferring, Gilead, Hospira, Immunic, Janssen, MSD, Nestle, Pfizer, Shire, Takeda, and Vifor.

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⁸ Department of Gastroenterology, Canberra Hospital, Canberra, Australia

⁹ Faculty of Science, Health and Engineering, University of Sunshine Coast, Sippy Downs, Australia

¹⁰ IBD Service, Department of Gastroenterology and Hepatology, Royal Adelaide Hospital, Adelaide, Australia

*corresponding author

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ABSTRACT

Background: Quality of care in IBD has received much attention internationally, however, the available surveys focus on health professionals rather than patients.

Aims: The study aimed to assess the experiences of health care for people living with inflammatory bowel disease (IBD) against established Australian IBD Standards.

Methods: An online cross-sectional survey was conducted with Australians ≥ 16 years old recruited via Crohn's & Colitis Australia membership, public and private clinics and the Royal Flying Doctor Service. Participants completed a questionnaire incorporating items addressing the Australian IBD Standards 2016, the Picker Patient Experience Questionnaire, IBD Control Survey, and the Manitoba Index.

Results: Complete data was provided by 731 respondents (71.5% female, median age 46 years, ranging from 16 to 84 years). While the majority (74.8%) were satisfied with their IBD healthcare, the care reported did not meet the Australian IBD Standards. Overall, 32.4% had access to IBD nurses, 30.9% to a dietitian, and 12% to a psychologist in their treating team. Participants managed by public IBD clinics were most likely to have access to an IBD nurse (83.7%), helpline (80.7%), and research trials (37%). A third of respondents reported waiting >14 days to see a specialist when their IBD flared. Participants received enough information; mostly from medical specialists (88.8%) and IBD nurses (79.4%). However, 51% wanted to be more involved in their healthcare.

Conclusions: These data show discordance between expectations of patients and national standards with current levels of service provision which fail to deliver equitable and comprehensive IBD care.

Keywords: inflammatory bowel disease; IBD standards; quality of care; multidisciplinary care; survey

INTRODUCTION

Inflammatory bowel disease (IBD) is a chronic relapsing condition, with the overall incidence rate in Australia of 29.3 per 100,000¹. People living with IBD are variably affected by chronic pain, diarrhoea, with frequent bowel movements, weight loss, anaemia and fatigue, significantly impairing their quality of life². In Australia alone, IBD is associated with the costs of \$380 million in productivity losses and further \$2.7 billion with its management each year³.

Quality of care in IBD has received much attention internationally, with a recent systematic review⁴ identifying 62 papers referring to IBD quality of care standards. These commonly recommend a multidisciplinary approach to care, appropriate referral pathways and improved access to helplines. In Australia, the Australian IBD Standards⁵ set the benchmark for national quality of care in IBD. However, a recent national audit of hospital- and clinician-based IBD care led by Crohn's & Colitis Australia (CCA) found it to fall short of national standards^{6,7}. A major gap was identified in access to multidisciplinary services, including psychological support. Of note, those IBD services with even a partial IBD-Team, defined as a clinical lead, some IBD nurse time and a helpline, provided improved care compared to those that did not. In particular, the partial IBD-Team services noted significantly fewer admissions through emergency departments (58% vs. 74%) and better adherence to safety monitoring of biological (89% vs. 59%) and immunosuppressive (79% vs. 55%) treatments. Services with a partial IBD-Team also offered better access to combined medical-surgical outpatient reviews, multidisciplinary meetings to discuss complex patients, clinical trials and databases, and better provision of educational materials and information who to contact in the event of a flare-up.

The patient perspective complements the hospital-based audit⁶. Patient-centred care⁸ and consumer involvement in health⁹ improve the safety and quality of healthcare. Therefore, we initiated a two-stage project to study the experience of healthcare of people living with IBD in Australia. Stage one was undertaken in 2017 and utilised the Consumer Health Forum 'Real People Real Data Toolkit'¹⁰ to collect and analyse patient stories to contribute to practical evidence. The themes identified in this study¹¹ were used to inform Stage Two of the project – the present quantitative national survey of patient experience. To our knowledge, this study

was the first Australian national survey exploring the patient experience of healthcare for people living with IBD. The specific aims of the study were to:

- Assess the experience of health care for people living with IBD against established standards;
- Compare the patient experience of health care for people in different service settings.

MATERIALS AND METHODS

Design

An exploratory online cross-sectional survey was conducted in June-August 2018.

Selection criteria

All people diagnosed with Crohn's disease, ulcerative colitis, or indeterminate colitis (self-reported) aged 16 or above were eligible to participate in the survey. Participants were required to receive their health care in Australia.

Recruitment

Recruitment of participants was promoted to Crohn's & Colitis Australia members and associated social media, public and private IBD, general gastroenterology and other medical clinics and specialist practices throughout Australia and the Royal Flying Doctor Service, using flyers, newsletters and electronic media.

Measures

We developed a questionnaire incorporating newly designed questions relating to the Australian IBD Standards 2016⁵. In addition, we used seven questions from the Picker Patient Experience Questionnaire (PPE-15)¹². The PPE-15 is a 15-item questionnaire measuring experience of in-patient care in any type of hospital for any type of patient. It is intended to be combined with other scales.

We used the IBD Control Survey and Manitoba Index to measure patients' subjective disease activity. The IBD Control survey¹³ is a validated patient-reported outcome measure (PROM), with two subscales: IBD-Control-8 (0-16, with 0 meaning worst control, with a cut-off for remission ≥ 13 points) and IBD-Control-VAS (0-100, with 0 meaning worst control, with a cut-off for remission of ≥ 85). The Manitoba index¹⁴ is a validated single-item, patient-defined disease activity measure.

Data analysis

A large proportion of the analysis was descriptive, where means (SD)/medians (IQR) and frequencies (%) were used to describe the sample. Independent student t-test, one-way ANOVA (or non-parametric equivalents) and chi-square test were used to compare patient experience of health care for people in different service settings.

ETHICAL CONSIDERATIONS

The study was approved by the Research Ethics Committee and was performed in accordance with the Declaration of Helsinki (as revised in Brazil 2013). Participants gave informed consent before completing the survey.

RESULTS

In total, 1024 individuals accessed the survey. Of these, 264 did not progress beyond the initial questions and a further 22 progressed yet completed fewer than 50% of questions. These 286 incomplete responses were removed from further analysis. Three respondents stated they had neither CD, UC nor IC and were also removed. Four respondents were younger than 16 years old and were removed from further analysis. The final analysis was conducted using 731 cases.

Demographics

The respondents were mainly female (71.5%), university-educated (45.9%), married / de facto (65.1%), employed full-time (34.1%), and current members of CCA (63.1%) (**Table 1**). The median age was 46 years (range 16-84, IQR 34-58). Respondents came from each state and territory.

Clinical characteristics

There was a slight predominance of respondents with CD (57.6%) (**Table 2**). According to the Manitoba Index, most participants (69.6%) had active IBD. According to IBD-Control-8, 63.2% had active IBD, while according to the IBD-Control-VAS, 60.3% had active IBD.

IBD healthcare satisfaction

Most respondents (74.8%) were satisfied with the IBD healthcare they received.

Measuring patient experience against the Australian IBD Standards

Standard A: High-quality clinical care

A1 The IBD team & A2 Essential Supporting Services

The IBD team available to these respondents included gastroenterologists (97%), and less frequently an IBD nurse (32.4%), dietitian (30.9%), colorectal surgeon (26.3%) and pharmacist (26.1%). Twelve percent of patients had access to psychologists and 10.3% to stoma nurses with 5.6% of respondents reporting having a current stoma (**Figure 1**). Respondents managed by public hospital IBD outpatient clinics reported the highest access to IBD nurses (83.7%), dietitians (48.9%) and stoma nurses (20.6%) ($p < 0.001$) [see **Supplementary Table 1**].

Overall, 39.9% of respondents had taken steroids for more than six weeks in the last year, with those treated predominantly by GPs least likely to take steroids – 25% vs. 44% of those treated by private specialists ($p = 0.038$). Further, 45.3% were currently taking immunomodulators and 38.7% took biologics, 9% took opiates and 18.3% took psychotropics (**Supplementary Table 2**).

A5 Access to nutritional support and therapy

Overall, 30.9% of respondents had access to a dietitian. For inpatients, 38.3% were seen by a dietitian whilst in hospital (see A8/10).

A6 Arrangements for the use of biological therapies

Biologic therapies were being taken by 38.7% of respondents and a further 4% had taken them in the last year but ceased. These were prescribed by gastroenterologists predominantly, with a small number prescribed by rheumatologists or dermatologists (**Supplementary Table 2**).

A8 Inpatient facilities & A10 Inpatient care

About a quarter of respondents had an in-hospital stay in the last year and for the majority of those (77.6%), this was an unplanned admission. Inpatient facilities and services varied. For the minority (30.1%), their bed was situated in the gastroenterology ward. Toilet facilities were seen as adequate by 71.4%. Close to 40% were seen by a dietitian and 24.5% by an IBD nurse

in hospital. Nearly 36% of those who had surgery received what they regarded as adequate information before the procedure. In many cases (47.4%), family / friends of the hospitalised IBD patient were informed about how to help them recover (see **Supplementary Tables 3 and 4**).

A9 Access to diagnostic services

Most respondents (74.1%) had chosen to have a colonoscopy through the private healthcare system with half of them (50.3%) reporting this being to expedite the procedure.

A11 Outpatient care

The majority of respondents (81.9%) were reviewed for their IBD at least once a year and an IBD helpline (includes direct contact with specialists) was available to just over 50% of respondents (**Table 3**). For 30.8% of participants, a wait of more 14 days to see their specialist when experiencing relapse was reported.

A14 General practice communication (see Standard B1)

Standard B: Local delivery of care

B1 Arrangements for shared-care (including A14 General Practice communication)

Nearly 70% reported that their GP was involved in their IBD care, although 26% of respondents were not confident as to which issues they should consult on with their GP and which with their specialist (**Supplementary Table 5**). Those with access to an IBD nurse were more commonly clear regarding which issues to discuss with whom compared with those without IBD nurse access (82.4% vs 69.5%, $p < 0.01$) (**Supplementary Table 6**).

Standard C: Maintaining a patient-centred service

C2 Rapid access to specialist advice

C3 Supporting patients to exercise choice between treatments

C4 Supporting patients to exercise choice between different follow-up care models

C5 involvement of patients in service improvement

An IBD helpline was available to just over 50% of respondents (**Table 4**). Overall, 63.1% felt they had a choice in their treatment, but 51% would like to be more involved in decisions about their care and treatment.

Approximately one third of the respondents used complementary and alternative medicines (CAMs) and about 30% of doctors asked about CAMs use. Overall, 44.3% of the respondents had not been given a choice on how to participate in follow up care (e.g. specialist rooms, outpatient clinic or GP shared care) but were nonetheless happy with the way follow up care was delivered. Most participants (75.2%) have never been asked for feedback on their IBD care.

Those with access to an IBD nurse more commonly also had access to an IBD helpline (77.1% vs 45.2%, $p<0.001$), choice in treatment (70.6% vs 60.2, $p<0.05$) and were asked for feedback (32.3% vs. 10.9%, $p<0.001$) than those without. Those with IBD nurse access also less commonly used CAMs than those without (26% vs 36.5%, $p<0.05$) (**Supplementary Table 6**). Respondents managed by a private specialist most commonly used CAMs (35.9%) compared to public outpatients (24.2%), public IBD clinic patients (25%) and GP-managed patients (28.1%) ($p<0.01$) (**Supplementary Table 1**).

Standard D: Patient education and Support

D1 Provision of Information

Most participants (87%) had their care and treatment options explained to them (**Table 5**). Overall, 72.1% received printed information about IBD and 49.8% had a plan of what to do if their condition deteriorated. Respondents with access to an IBD nurse more commonly reported having care options explained than those without (58.7% vs 41.3%, $p<0.001$) (**Supplementary Table 6**). Most participants received enough information when required from their specialist (88.8%) and their IBD nurse (79.4%) (**Supplementary Table 7**).

D2 Education for patients & D3 Patient Support Groups

Overall, 35% of respondents reported feeling they could access IBD educational forums and 56.1% took the opportunity to attend such a forum (**Supplementary Table 8**). Regarding accessing online IBD resources, 51% reported that they regularly access online IBD forums or websites for IBD information.

Standard F: Evidence-based practice and research

Overall, 17% reported being offered the opportunity to receive treatment through a research trial. A high proportion (67.7%) of those offered trial participation accepted. The opportunity to participate in a research trial was greater in public IBD clinics (37.1%) compared with general public outpatients (21.2%), private specialist patients (13.2%) and GP managed patients (3.1%) ($p<0.001$) (see **Supplementary Table 1**), and also for those with access to an IBD nurse compared to those without (30.2% vs 10.9%, $p<0.001$) (**Supplementary Table 6**).

DISCUSSION

Quality of care in IBD has received much attention internationally as evidenced by a recent systematic review of 62 papers⁴, however, the available surveys focus on health professionals rather than patients¹⁵⁻¹⁷, with very few large-scale patient-focused studies available. The largest to date European survey (n=4,670)¹⁸ examined quality of life (impact on life and work), access to healthcare, medication use, and communication with a physician, overlapping with some of the questions in our present study. A Canadian study (n=837)¹⁹ focused on hospital-related outcomes such as VTE prophylaxis and C. difficile testing and the need for surgery. A UK audit (n=1550)²⁰ documented experience of hospital care – satisfaction with hospitalisation, trust in hospital staff and the role of nurses, pain, satisfaction with hospital food, hospital discharge experience. While the quality of care with in-hospital IBD care has been examined in the Australian context before⁶, the present study is the first and largest Australia-wide survey of quality of care in outpatient IBD.

Importantly, for many respondents in this survey, the experience of care did not meet the level described in the Australian IBD Standards 2016⁵, in particular, standards of care were not met in various areas including multidisciplinary care, responsiveness, choice in care and clinical communication. These data correspond directly with the findings of the recent Australian hospital-based audit of IBD care⁶.

Multidisciplinary care

Multidisciplinary integrated care is the current best practice in managing chronic illness²¹. In the recent Australian hospital-based audit of IBD care⁶, those services with multidisciplinary care provided better care in comparison to those relying on a single person to provide care. In this patient survey, the earlier findings are confirmed with a third of respondents reporting access to IBD nurses or a dietitian and fewer (12%) having a psychologist or a stoma nurse (10.3%) in their team. These rates are consistent with the low levels of access described in the hospital-based audit⁶ (4% of sites had a psychologist in the team). IBD is negatively affected by mental health issues, resulting in more frequent flares²², a more aggressive presentation²³,

increased hospital readmissions and increased risk of surgery²⁴. Mental and physical healthcare can no longer be separated in IBD and most international IBD treatment guidelines acknowledge this fact²⁵. On the other hand, this limited access to these allied health specialists may reflect the lack of need to utilise the services of these professionals, for example, only just over five percent of our respondents had a stoma and therefore would not have had a need to be in touch with a stoma nurse. Further, patients who are hospitalised often see multiple health professionals, so may, for example, not recall having seen a dietitian or IBD nurse at the time. These data should therefore be interpreted with caution.

Care settings

For this survey's respondents, the best access to a multidisciplinary team was via public IBD clinics. In particular, those treated in public IBD clinics had better access to an IBD nurse, were more likely to have access to a helpline and to participate in research trials than those receiving care in other settings. While none of the care settings, overall, identified by survey respondents met the standard for multidisciplinary care, IBD nursing or helpline, there is significant variability in access for participants both across and within service settings. For example, those with access to an IBD nurse were more likely to also have access to a helpline and to have their care options explained than those without IBD nurse access; although IBD nurse access did not guarantee these items. In several recent studies²⁶⁻²⁹, access to an IBD nurse has been reported to reduce healthcare utilisation and improve quality of care, resulting in cost savings. Interestingly, in the present survey those with access to an IBD nurse less commonly used CAMs than those without this access, and CAMs use is often a reflection of poor health status³⁰ and lack of satisfaction with conventional IBD care³¹. Expanding access to IBD nurses is therefore an important strategy in improving patient outcomes.

Responsive/Proactive Care

Another area of concern was responsiveness of care. While it is an IBD standard that specialist advice is available to those with a possible relapse within 5 days, a third of respondents had to wait more than 14 days to see a specialist. A half those surveyed had an action plan for if their condition deteriorated. The availability of IBD helplines was limited to just over 50% of

respondents, which is consistent with the IBD Audit⁶ reporting availability of helplines in half the sites.

Of note, more than a quarter of respondents had been admitted overnight in the past year and of those, more than three quarters were unplanned or emergency admissions. This is higher than found in the IBD Audit⁶ emergency admission rate of 60%, and may reflect a response bias either from the better-resourced hospital sites completing the prior audit or from patients with worse care experiences deciding to participate in the survey. Regardless, these rates for unplanned/emergency admission are high and indicate a critical area for attention in terms of care quality. Responsive and proactive care is important in IBD to improve the disease burden but also to reduce high healthcare costs²⁸.

Choice in care and clinical communication

Other gaps in current IBD care relate to clinical communication and choice in care. Most respondents in this survey reported that they had their care treatment explained but the quality of the information and their involvement in decision making varied. Nearly two-thirds of patients had a choice in their treatments which is consistent with the IBD audit⁶ where 64% of sites said they actively encouraged involvement in care decisions. However, 51% of respondents in this survey wanted to be more involved in decisions about their treatment. This again reinforces the need for an integrated approach to care, which relies heavily on patient involvement and is patient-centred²¹.

Overall Satisfaction

Finally, despite the variability in the experience of care, 74.8% reported being satisfied with the IBD healthcare they received. Given the gaps in care quality identified by the audit of care actually experienced against the IBD Standards, it appears that patients are unaware of the Standards in particular and the specific components of Quality in general. This lack of consumer awareness makes it difficult for patients to become their own effective advocates. Generally, patient satisfaction questions ask patients to give subjective responses and are more influenced by expectations rather than facts; whereas patient experience is concerned with what

did or did not occur during health care^{32, 33}. The present data highlight the need to improve awareness to raise the expectations of care so that individuals do not accept as normal: active disease; unresponsive healthcare provision; and a lack of choice and involvement in decision-making.

Limitations of this study

The age restriction made us unable to extrapolate to the paediatric setting. Severity of disease was classified according to validated patient expressed measures but lacked objective measures because all data were collected by self-reporting. IBD-Control-8 and IBD-Control-VAS have moderate-to-strong correlations with well-established and commonly used disease indices such as the Harvey-Bradshaw Index and Simple Clinical Colitis Activity Index¹³. Likewise, the Manitoba index correlates highly with other common disease activity indices¹⁴. While these disease activity indices are subjective and therefore not universally reliable, research has shown that they correlate with objective markers of disease activity such as c-reactive protein³⁴ or faecal calprotectin³⁵, though the correlations appear stronger using UC-specific rather than CD-specific indices³⁶, and therefore can substitute objective measures when they are not attainable (e.g., online data collection). Similarly, a diagnosis of IBD was not confirmed, with reliance on patient self-report. There was low participation from people in remote areas. It is likely that their experience would be more negative than the present respondents' due to lack of access, although these respondents might also have had negative experiences making them more likely to respond. The female participation rate was high in this survey, which is consistent with most survey studies but means that males with IBD are not fully represented. Similarly, the relatively high educational achievement of these respondents means that the data may not be generalizable to those with lower levels of education. Online data collection excludes potential participants who do not access online surveys and thus these data are applicable to those who use the internet. Nevertheless, in Australia 86% of population uses the internet at home³⁷ and thus online studies can be relatively representative.

Conclusion

This large survey examined the quality of care in IBD in Australia against the established IBD Standards. The survey showed that while most respondents were satisfied with their IBD healthcare, the care reported did not meet the Australian IBD Standards. The present data highlight the need to improve awareness to raise the expectations of care so that individuals do not accept as normal: active disease; unresponsive healthcare provision; and a lack of choice and involvement in decision-making.

REFERENCES

1. Wilson J, Hair C, Knight R, Catto-Smith A, Bell S, Kamm M, et al. High incidence of inflammatory bowel disease in Australia: a prospective population-based Australian incidence study. *Inflammatory bowel diseases*. 2010;16(9):1550-6.
2. Knowles SR, Graff LA, Wilding H, Hewitt C, Keefer L, Mikocka-Walus A. Quality of Life in Inflammatory Bowel Disease: A Systematic Review and Meta-analyses-Part I. *Inflammatory bowel diseases*. 2018;24(4):742-51.
3. PricewaterhouseCoopers. Improving Inflammatory Bowel Disease care across Australia. Melbourne: Crohn's & Colitis Australia, 2013.
4. Fiorino G, Allocca M, Chaparro M, Coenen S, Fidalgo C, Younge L, et al. 'Quality of Care' Standards in Inflammatory Bowel Disease: A Systematic Review. *Journal of Crohn's & colitis*. 2019;13(1):127-37.
5. CCA. Australian IBD Standards: Standards of healthcare for people with inflammatory bowel disease in Australia. Camberwell, VIC, Australia: Crohn's & Colitis Australia, 2016.
6. CCA. Final report of the first audit of the organisation and provision of IBD services in Australia. Camberwell: Crohn's & Colitis Australia, 2016.
7. Massuger W, Moore GT, Andrews J, Kilkenny M, Reyneke M, Knowles S, et al. The Crohn's & Colitis Australia Inflammatory Bowel Disease Audit: Measuring the quality of care in Australia. *Internal medicine journal*. 2018.
8. Randall R. Consumer co-creation in health: innovating in Primary Health Networks. Deakin, ACT: Deeble Institute for Health Policy Research, Australian Healthcare and Hospitals Association, 2016.
9. Schoultz M, Macaden L, Watson AJ. Co-designing inflammatory bowel disease (Ibd) services in Scotland: findings from a nationwide survey. *BMC health services research*. 2016;16:231.
10. Real People Real Data Toolkit: Consumer Health Forum of Australia; 2017 [29/03/2018]. Available from: <https://chf.org.au/real-people-real-data-toolkit>
11. care MISC-cl. Camberwell: Crohn's & Colitis Australia; 2017 [22/03/2018]. Available from: <https://www.crohnsandcolitis.com.au/ibdqc/my-ibd-story-co-creating-ibd-care/>
12. Jenkinson C, Coulter A, Bruster S. The Picker Patient Experience Questionnaire: development and validation using data from in-patient surveys in five countries. *Int J Qual Health Care*. 2002;14(5):353-8.
13. Bodger K, Ormerod C, Shackcloth D, Harrison M. Development and validation of a rapid, generic measure of disease control from the patient's perspective: the IBD-Control questionnaire. *Gut*. 2014;63:1092-102.
14. Clara I, Lix LM, Walker JR, Graff LA, Miller N, Rogala L, et al. The Manitoba IBD Index: evidence for a new and simple indicator of IBD activity. *The American journal of gastroenterology*. 2009;104(7):1754-63.
15. Song HK, Lee KM, Jung SA, Hong SN, Han DS, Yang SK. Quality of care in inflammatory bowel disease in Asia: the results of a multinational web-based survey in the 2(nd) Asian Organization of Crohn's and Colitis (AOCC) meeting in Seoul. *Intestinal research*. 2016;14(3):240-7.
16. Casellas F, Ginard D, Vera I, Torrejon A. Satisfaction of health care professionals managing patients with inflammatory bowel disease. *J Crohns Colitis*. 2013;7(7):e249-55.
17. Mikocka-Walus A, Andrews JM, Rampton D, Goodhand J, van der Woude J, Bernstein CN. How can we improve models of care in inflammatory bowel disease? An international survey of IBD health professionals. *J Crohns Colitis*. 2014;8(12):1668-74.

18. Lonnfors S, Vermeire S, Greco M, Hommes D, Bell C, Avedano L. IBD and health-related quality of life -- discovering the true impact. *J Crohns Colitis*. 2014;8(10):1281-6.
19. Nguyen GC, Murthy SK, Bressler B, Lam MCW, Alali A, Toumi A, et al. Quality of Care and Outcomes Among Hospitalized Inflammatory Bowel Disease Patients: A Multicenter Retrospective Study. *Inflammatory bowel diseases*. 2017;23(5):695-701.
20. RCP. Inpatient experience as reported by patients with ulcerative colitis throughout the UK. UK IBD audit. . London: Royal College of Physicians, 2014.
21. Grone O, Garcia-Barbero M. Integrated care: a position paper of the WHO European Office for Integrated Health Care Services. *International journal of integrated care*. 2001;1:e21.
22. Bernstein CN, Singh S, Graff LA, Walker JR, Miller N, Cheang M. A prospective population-based study of triggers of symptomatic flares in IBD. *The American journal of gastroenterology*. 2010;105(9):1994-2002.
23. Kochar B, Barnes EL, Long MD, Cushing KC, Galanko J, Martin CF, et al. Depression Is Associated With More Aggressive Inflammatory Bowel Disease. *The American journal of gastroenterology*. 2018;113(1):80-5.
24. Ananthakrishnan AN, Gainer VS, Perez RG, Cai T, Cheng SC, Savova G, et al. Psychiatric comorbidity is associated with increased risk of surgery in Crohn's disease. *Alimentary pharmacology & therapeutics*. 2013;37(4):445-54.
25. Hauser W, Moser G, Klose P, Mikocka-Walus A. Psychosocial issues in evidence-based guidelines on inflammatory bowel diseases: a review. *World journal of gastroenterology*. 2014;20(13):3663-71.
26. Coenen S, Weyts E, Vermeire S, Ferrante M, Noman M, Ballet V, et al. Effects of introduction of an inflammatory bowel disease nurse position on the quality of delivered care. *European journal of gastroenterology & hepatology*. 2017;29(6):646-50.
27. Molander P, Jussila A, Toivonen T, Makkeli P, Alho A, Kolho KL. The impacts of an inflammatory bowel disease nurse specialist on the quality of care and costs in Finland. *Scandinavian journal of gastroenterology*. 2018;53(12):1463-8.
28. Sack C, Phan VA, Grafton R, Holtmann G, van Langenberg DR, Brett K, et al. A chronic care model significantly decreases costs and healthcare utilisation in patients with inflammatory bowel disease. *Journal of Crohn's & colitis*. 2012;6(3):302-10.
29. Leach P, De Silva M, Mountfield R, Edwards S, Chitti L, Fraser RJ, et al. The effect of an inflammatory bowel disease nurse position on service delivery. *Journal of Crohn's & colitis*. 2014;8(5):370-4.
30. Harris PE, Cooper KL, Relton C, Thomas KJ. Prevalence of complementary and alternative medicine (CAM) use by the general population: a systematic review and update. *International journal of clinical practice*. 2012;66(10):924-39.
31. Rawsthorne P, Shanahan F, Cronin NC, Anton PA, Lofberg R, Bohman L, et al. An international survey of the use and attitudes regarding alternative medicine by patients with inflammatory bowel disease. *The American journal of gastroenterology*. 1999;94(5):1298-303.
32. ACSQHC. Australian Commission on Safety and Quality in Health Care Review of patient experience and satisfaction surveys conducted within public and private hospitals in Australia. Canberra: Australian Commission on Safety and Quality in Health Care, 2012.
33. Doyle C, Lennox L, Bell D. A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. *BMJ open*. 2013;3(1).

34. Bennebroek Evertsz F, Nieuwkerk PT, Stokkers PC, Ponsioen CY, Bockting CL, Sanderman R, et al. The patient simple clinical colitis activity index (P-SCCAI) can detect ulcerative colitis (UC) disease activity in remission: a comparison of the P-SCCAI with clinician-based SCCAI and biological markers. *Journal of Crohn's & colitis*. 2013;7(11):890-900.
35. Verdejo C, Hervias D, Roncero O, Arias A, Bouhmidi A, Lorente R, et al. Fecal calprotectin is not superior to serum C-reactive protein or the Harvey-Bradshaw index in predicting postoperative endoscopic recurrence in Crohn's disease. *European journal of gastroenterology & hepatology*. 2018;30(12):1521-7.
36. Taleban S, Stewart KO, Li DK, Singh P, Pardi DS, Sturgeon HC, et al. Clinical Activity and Quality of Life Indices Are Valid Across Ulcerative Colitis But Not Crohn's Disease Phenotypes. *Digestive diseases and sciences*. 2016;61(9):2627-35.
37. ABS. Household Use of Information Technology, Australia, 2016-17 Canberra: Australian Bureau of Statistics; 2018. Available from: <http://www.abs.gov.au/ausstats/abs@.nsf/mf/8146.0?OpenDocument>.

TABLES

Table 1: Demographic characteristics

		IBD (n=731)
Age, mean (SD), range (in years)		46.5 (15.5), 16-84
Sex, n (%)	Female	523 (71.5)
	Male	206 (28.2)
	Other	2 (0.3)
Education, n (%)	< Year 12	104 (14.2)
	Year 12	128 (17.5)
	Vocational / TAFE	123 (16.8)
	Bachelor degree	255 (34.9)
	Master degree	67 (9.2)
	PhD / doctorate	13 (1.8)
	Other (diploma / certificate)	41 (5.6)
Marital status	Single (never married)	175 (23.9)
	Married / de facto	476 (65.1)
	Widowed	16 (2.2)
	Divorced	42 (5.7)
	Separated	19 (2.6)
	Other	3 (0.4)
Employment	Full time	249 (34.1)

	Part time	158 (21.6)
	Unemployed and currently looking for work	16 (2.2)
	Unemployed and currently not looking for work	17 (2.3)
	Student	55 (7.5)
	Retired	107 (14.6)
	Homemaker	28 (3.8)
	Self-employed	42 (5.7)
	Unable to work	48 (6.6)
	Other	11 (1.5)
Language	English	718 (98.2)
Location †	Major cities of Australia	522 (71.5)
	Inner regional Australia	155 (21.2)
	Outer regional Australia	45 (6.2)
	Remote/very Remote	8 (1.1)
Location by state	Australian Capital Territory	22 (3)
	New South Wales	261 (35.7)
	Northern Territory	6 (0.8)
	Queensland	134 (18.3)

	South Australia	42 (5.7)
	Tasmania	21 (2.9)
	Victoria	202 (27.6)
	Western Australia	43 (5.9)
Current member of Crohn's & Colitis Australia		461 (63.1)

† remoteness categories defined according to the Australian Statistical Geography Standard (ASGS) Volume 5 – Remoteness Structure (cat. no. 1270.0.55.005) publication

Table 2: Clinical characteristics

		IBD (n=731)
IBD type, n (%)	Crohn's disease	421 (57.6)
	Ulcerative colitis	287 (39.3)
	Indeterminate colitis	23 (3.1)
Disease duration, mean (SD), range (in years)		14.2 (11.5), 1-63
Stoma, n (%)		41 (5.6)
Fistula, n (%)		47 (6.4)
Perianal disease, n (%)		51 (7)
Manitoba Index, n (%)	Inactive IBD	222 (30.4)
	Active IBD	509 (69.6)
Manitoba index subcategories, n (%)	Constantly active, giving me symptoms every day	111 (15.2)
	Often active, giving me symptoms most days	140 (19.2)
	Sometimes active, giving me symptoms on some days (for instance 1 – 2 days / week)	156 (21.3)

	Occasionally active, giving me symptoms 1 – 2 days / month	102 (14)
	Rarely active, giving me symptoms on a few days in the past 3 months	90 (12.3)
	I was well in the past 3 months, what I consider a remission or absence of symptoms	132 (18.1)
IBD-control-8, n (%)	Inactive IBD (≥ 13)	269 (36.8)
	Active IBD (< 13)	462 (63.2)
IBD-control-8, mean (SD)	Range 0-16, with 0 meaning worst control	9.8 (4.9)
IBD-Control-VAS, n (%)	Inactive IBD (≥ 85)	290 (39.7)
	Active IBD	441 (60.3)
IBD-Control-VAS, mean (SD)	Range 0-100, with 0 meaning worst control	71.9 (25.5)

Table 3: Outpatient care

		IBD (n=731)
		n (%)
A11 Is there a plan for your IBD to be reviewed at least once per year even if you are well?	Yes	599 (81.9)
	No	85 (11.6)
	Unsure	45 (6.2)
A11 Last time you had a relapse of your IBD, how long did it take to get to see your specialist?	1-2 days	156 (21.3)
	3-5 days	160 (21.9)
	6-14 days	188 (25.7)
	More than 14 days	225 (30.8)
A11 C2 Does your treating team provide access to an email or telephone help line where you get a response by the end of the next day?	Yes	405 (55.4)
	No	196 (26.8)
	Unsure	128 (17.5)

Table 4: Patient-centred services

		IBD (n=731)
		n (%)
C2 Does your treating team provide access to an email or telephone help line where you get a response by the end of the next day?	Yes	405 (55.4)
	No	196 (26.8)
	Unsure	128 (17.5)
C3 Do you have a choice in what treatment you have?	Yes	461 (63.1)
	No	64 (8.8)
	Unsure/I've never asked	123 (16.8)
	I'd rather the doctor decided	77 (10.5)
C2 Did you want to be more involved in decisions about your care and treatment?	Yes	373 (51)
	No	222 (30.4)
	Unsure	130 (17.8)
C3 Do you use any complementary therapies?	Yes	239 (32.7)
	No	441 (60.3)
	Unsure	45 (6.2)
C3 Does your doctor ask what complementary therapies you use, if any?	Yes	222 (30.4)
	No	439 (60.1)
	Unsure	64 (8.8)
	Yes	177 (24.2)

C4 Have you been given a choice on how you participate in follow up care, e.g. specialist rooms, outpatient clinic or GP shared care?	No, I'd like a choice	147 (20.1)
	No, but I'm happy with the way follow up care is delivered	324 (44.3)
	Unsure	77 (10.5)
C5 Have you ever been asked for feedback about your IBD care such as a survey, feedback card, web form, open day?	Yes	130 (17.8)
	No	550 (75.2)
	Unsure	45 (6.2)

Table 5: Provision of Information

		IBD (n=731)
		n (%)
D1 Has a member of your treatment team explained your care and treatment options?	Yes, completely	341 (46.6)
	Yes, to some extent	299 (40.9)
	No	61 (8.3)
	I didn't need an explanation	23 (3.1)
D1 Does your treating team provide an opportunity for your family/carer to be involved in education/information sharing?	Yes, completely	203 (27.8)
	Yes, to some extent	150 (20.5)
	No	197 (26.9)
	They didn't need to be involved	174 (23.8)
D1 Have you ever been given printed information about IBD?	Yes	527 (72.1)
	No	158 (21.6)
	Unsure	39 (5.3)
D1 Do you have an agreed plan with your treating team about what to do if your symptoms worsen, or you experience treatment side effects?	Yes	364 (49.8)
	No	270 (36.9)
	Unsure	90 (12.3)

FIGURES **Figure 1:** Specialists available in the IBD team

ABSTRACT

Background: Quality of care in IBD has received much attention internationally, however, the available surveys focus on health professionals rather than patients.

Aims: The study aimed to assess the experiences of health care for people living with inflammatory bowel disease (IBD) against established Australian IBD Standards.

Methods: An online cross-sectional survey was conducted with Australians ≥ 16 years old recruited via Crohn's & Colitis Australia membership, public and private clinics and the Royal Flying Doctor Service. Participants completed a questionnaire incorporating items addressing the Australian IBD Standards 2016, the Picker Patient Experience Questionnaire, IBD Control Survey, and the Manitoba Index.

Results: Complete data was provided by 731 respondents (71.5% female, median age 46 years, ranging from 16 to 84 years). While the majority (74.8%) were satisfied with their IBD healthcare, the care reported did not meet the Australian IBD Standards. Overall, 32.4% had access to IBD nurses, 30.9% to a dietitian, and 12% to a psychologist in their treating team. Participants managed by public IBD clinics were most likely to have access to an IBD nurse (83.7%), helpline (80.7%), and research trials (37%). A third of respondents reported waiting >14 days to see a specialist when their IBD flared. Participants received enough information; mostly from medical specialists (88.8%) and IBD nurses (79.4%). However, 51% wanted to be more involved in their healthcare.

Conclusions: These data show discordance between expectations of patients and national standards with current levels of service provision which fail to deliver equitable and comprehensive IBD care.

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Author/s:

Mikocka-Walus, A;Massuger, W;Knowles, SR;Moore, GT;Buckton, S;Connell, W;Pavli, P;Raven, L;Andrews, JM

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