2017

"My IBD Story"
Co-creating IBD care

A report by Crohn's & Colitis Australia

Quality of Care Program

November 2017

Crohn's & Colitis Australia (CCA) is a not-for-profit organisation that supports 80 000 people living with Crohn's disease and ulcerative colitis. Established in 1985 the organisation delivers support programs such as education, advocacy, counselling, increasing awareness, and generating and utilising funds for research and support. CCA, the peak national group representing people with inflammatory bowel disease (IBD), engages with the key stakeholders in IBD care and services including its members, others living with IBD, medical and healthcare professionals and their representative bodies, hospitals, primary health, State and Commonwealth governments, industry groups and the broader health advocacy sector. Visit **www.crohnsandcolitis.com.au** for more information about this report or CCA's programs and services.

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Quality of
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TABLE OF CONTENTS

ACKNOWLEDGEMENTS

Crohn’s & Colitis Australia (CCA) gratefully acknowledges the 20 participants who volunteered to tell their personal stories and make them public. Their willingness to give their time, sometimes when unwell, is commendable and will contribute to the greater understanding of healthcare for people living with IBD.

CCA also appreciates the work undertaken by the Consumer Health Forum in developing the *Real People Real Data Toolkit* that was used to guide this survey.

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This project was supported by unrestricted educational grants from **major supporter Ferring Pharmaceuticals,** and Abbvie.

EXECUTIVE SUMMARY

The stories of healthcare for people living with inflammatory bowel disease (IBD) are variable and include unacceptable experiences that point to serious deficiencies in the healthcare provided. The stories compel the need to improve quality of care to ensure the excellent healthcare experienced described by some, becomes the norm for all.

Crohn's disease and ulcerative colitis, collectively known as IBD, are a worldwide issue with Australia having amongst the highest prevalence in the world. These lifelong conditions have fluctuating symptoms that are often debilitating and can result in serious surgery. The ongoing, recurring nature of the conditions can result in significant psychological and social impacts. The hospital, healthcare and indirect costs associated with the 80 000 people living with IBD in Australia are over $2.5 billion annually. Importantly, the healthcare delivered to these people is inequitable and in many cases inadequate.

Research outcomes, new treatment options and service development have resulted in pockets of excellence in IBD care. To support the widespread improvement of the quality of care and improve equity, Crohn's & Colitis Australia lead a consortium of the peak learned bodies in IBD to establish Australian standards for IBD care and audited the organisation, resources and delivery of care nationally, using hospital data and medical records. These processes provided evidence for the improvement of care, but did not include evidence from the consumer perspective. The growing participation of consumers in their own health care and improvement of care, compels the healthcare industry to engage consumers to achieve the best possible quality improvement outcomes.

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This project undertook to interview people living with IBD about their experience of healthcare to provide practical evidence for the improvement of care.

Twenty interviews were conducted using a semi-structured format. Data was analysed using the Consumer Health Forum (CHF) indicators of consumer-centred care.

The findings described provide useful information for clinicians, hospitals, planners and funders to improve care, as well as identifying areas for further investigation and focus in future larger scale surveys.

Inequity of access to high quality care was apparent, in particular access to specialised services, rural service levels, and significant costs of care that are prohibitive for some. Where specialised services were available they were often highly regarded and were described as resulting in rapid diagnosis.

Participants described the importance of good information and understanding to successful management of their condition. Where information was lacking or absent, participants sourced their own information from reliable and unreliable sources. In some cases the lack of information resulted in significant suffering or mental anguish. In a number of stories, multidisciplinary teams and IBD nurses provided good, accessible information.

Instances where appropriate care was not delivered occurred in many participants experience. Diagnosis was not timely for a variety of reasons, but delay to gastroenterologist referral by GP or emergency department was a factor. Diagnosis was generally fairly rapid once the gastroenterologist was involved. Diagnostic confirmation was sometimes described as a great relief, removing longstanding uncertainty, but sometimes fraught with anxiety when inadequately explained.

Stories often described great satisfaction with gastroenterologists that were empathetic, responsive, provided effective disease management and engaged the participant in proactive planning in case of deterioration. Where this was not the case, participants attributed significant persistent or escalating symptoms directly to their management. Multidisciplinary care through specialised IBD teams was well regarded where present, but often not available. Ad hoc consultations with GPs and other health professionals were often variable with a lack of knowledge about IBD management evident.

A range of treatment and hospital related problems occurred to participants, though the impact of short and long term use of steroids deserves mention because it was described sometimes as the worst experience of the individual's story.

Sometimes ill participants had symptoms dismissed or disbelieved by generalist health care staff which had a significant impact on psychological and health care seeking behaviour. Commonly participants identified aspects of their healthcare and psychosocial journey that required attention outside of their gut health. Good GP or gastroenterologist management or referral to psychologists and other health professionals for 'non-gut' healthcare was effective. Unfortunately some participants had little or no attention to the impact of the gut disease on other important aspects of the health.

A few participants made specific mention of how they had input into their care decisions and been able to directly influence that care, and where this was not the case it led to frustration and most likely unnecessary suffering.

Collectively the stories provide a diverse range of positive and negative healthcare experiences that stakeholders can consider immediately and provide a compilation of issues for further larger scale examination (see page 27).

INTRODUCTION

This is a report summarising twenty interviews with people living with inflammatory bowel disease (IBD) about their experience of healthcare.

IBD is a collective term used for Crohn's disease and ulcerative colitis which are lifelong gastrointestinal disorders. The acute symptoms can be debilitating, often requiring hospitalisation and surgery. The symptoms can vary by nature and severity among patients, but commonly include diarrhoea, pain, bleeding, fatigue, weight loss, anaemia and bowel obstruction. The chronic, relapsing nature of the conditions has broader effects on an individual's physical and psychological health. Though there has been significant improvement in treatments over the last decade, immediate and long term side effects of treatment are a significant burden. The majority of cases are diagnosed before 40 years of age resulting in decades of disease-affected life.

IBD is an established global problem and Australia has a particularly high prevalence with more than 80,000 people estimated to be affected. PricewaterhouseCoopers found in 2012 that the disease had substantial costs for the Australian community with hospital costs estimated to be over $100 million; productivity losses over $380 million and total indirect costs over $2.7 billion[i]. Despite the expenditure, care is inconsistent and inadequate.

In response to inadequacies in the quality of IBD care Crohn's & Colitis Australia (CCA) undertook a national audit of processes, resources and delivery of IBD care in 2015-16. The objectives of the audit were to:

- Characterise the variability in current IBD care and resources.
- Identify the source of variations if found.

Results and recommendations of the audit were published in February 2017 to provide evidence for the improvement of quality of care. The full IBD Audit report[ii] is available at: www.crohnsandcolitis.com.au/ibdqoc/

The IBD Audit involved 71 hospital sites across Australia and gathered data from, hospital administrative systems, clinicians and the hospital medical records of over 1440 patients. The audit did not gather information from the patient perspective and recommended: "A survey of people living with IBD should be undertaken to identify the source of variation in care as it relates to the prevailing standards."

Considering patient experience is important to improving quality of care. An evidence brief published by the Consumer Health Forum Australia and the Deeble Institute for Health Policy Research explored a number of benefits to the healthcare system that arise from using co-creation* to deliver value and improve models of

> ***Co-creation is "a process whereby all stakeholders jointly contribute to the ideation, planning, implementation and evaluation of new services and systems as a possible means to optimise outcomes" [iii]***

care and noted that one way for consumers to be involved in co-creation is through measuring patient experience[iii]. Evidence included:

- Measuring and publishing the results of consumer experience surveys has been shown to increase the standard of care that practitioners provide.
- Not acting on feedback has been shown to have a damaging impact.
- Higher patient satisfaction is associated with improved guideline adherence and lower patient mortality rates.

Shortcomings in the collection of this data is supported by IBD Audit data that demonstrated only half of participating sites offered an opportunity for patients to provide feedback on their care, 17% involved patients in planning and improvement, 3% had an IBD patient panel and 12% had reported patient feedback of their care in the last year.

The quality and regularity of the collection of patient experience data varies widely. CCA developed a plan to explore the health care experience of people with IBD in two stages:

Stage 1	*Collect and analyse patient stories to develop practical evidence using the 'Real People Real Data' methodology.*
Stage 2	*Undertake an observational cross-sectional quantitative survey of the healthcare experience of people living with IBD using validated survey tools.*

This report describes the Stage 1 project known as My IBD Story.

Aim

To improve the quality of care for people living with IBD by examining the patient experience of healthcare for people living with IBD. This evidence and the data and recommendations of the national hospital IBD Audit conducted in 2016, are intended to provide a basis for improved, co-created IBD health care services for people with IBD.

Objectives

The objectives of the project are to:

- Complement the findings and recommendations of the 2016 national IBD Audit by collecting and analysing the stories of people living with IBD about their experience of healthcare.
- Publish practical evidence to inform appropriate resources, organisation and delivery of care to promote better experiences for IBD patients, and to increase confidence in the system, compliance and health literacy.
- Provide a platform for IBD patients to have input into the standard of IBD healthcare they receive.
- Provide information to guide the selection and development of suitable quantitative survey tools for Stage 2 of the CCA patient experience project.

METHODOLOGY

CCA used the methodology outlined in the Consumer Health Forum *'Real People Real Data Toolkit'*[iv] as a guide to collect and analyse patient stories. The toolkit aims to "support organisations to understand and use consumer stories to guide their strategic decision-making to develop practical evidence."

Study population

The target group was adults with Crohn's disease or ulcerative colitis, regardless of disease duration or severity of disease. Diagnosis was self-reported and not validated through other sources. Other inclusion criteria were:

- Experience of private or public health services in the management of their condition, regardless of whether the experience could be characterised as positive or negative.
- Carers/parents of young children were welcome to participate.
- Capable and available to participate in a telephone interview and review of transcript.
- Consent to participate.

Recruitment

Participants were recruited through CCA membership magazine promotion and social media promotion to the public. Fifty one people expressed interest in participating and provided the following limited information:

- Diagnosis
- Home address State
- Public, private or mixed health service utilisation
- Duration of disease
- Gender

Selection of interview participants aimed to achieve a range of the attributes listed above and the occurred on a consecutive basis where multiple options were available. Some people provided a high level of detail about their experience in their expression of interest which did not influence the selection process.

Data collection

The interviewer used The Patient Life Journey framework which uses semi structured interviews that follow stages of living with a health condition, in this case:

- A change in health
- Seeking assistance
- Diagnosis
- Treatment
- Life with a health issue

According to this model: medical, clinical, social, personal and community factors shape people's experience at each stage of the journey – and the overall experience and outcomes of their journey. The advantage of the life journey framework is that it allows consumers to tell a story about these multiple factors in their own words, but with reference to a simple framework that can help them to talk about their story.

Telephone interviews of 30-45 minutes duration were undertaken with each participant. Generally the participant was encouraged to describe their story as they saw fit but were asked to focus their comments on their experience of health care throughout their journey with IBD. An interview guide, Appendix 1, was used to ensure key areas were explored. The interviewer used active listening to clarify points or request more detail.

Notes and electronic recording were made by the interviewer and participants provided written consent to use the information. Transcripts of interviews were emailed to participants to verify that content accurately reflected the interview. Additionally participants were asked to highlight important positive or negative issues in each stage.

An example of a Patient Life Journey interview transcript is included in Appendix 2.

Data analysis

Stories were reviewed by the interviewer, and 'experience points' were identified which are occurrences that left a positive or negative impression on the participant. Each experience point was input into a 'Health Experience Wheel' format that allows quick and effective interpretation of positive and negative experience throughout the patient life journey stages. The Health Experience Wheels act as a visual adjunct to stories that highlight issues.

Positive and negative experience points were also allocated to one or more CHF indicators of consumer-centred care. These criteria reflect well-established understandings of the aspects of good care and good health that lead to good health outcomes. These criteria appear in many widely used domains of patient-centred care, and in authoritative typologies of the aspects and determinants of good health. These criteria also reflect CHF's experience as the national peak body representing health consumer interests. The criteria are as follows and are defined in Appendix 3:

1. Access, equity and affordability
2. Information and understanding
3. Informed consent (including informed financial consent)
4. Appropriate care
5. Respectful care
6. Whole of person care
7. Coordinated care and supported transitions
8. Safety and quality
9. Control and choice
10. Social, economic and community participation
11. Carers and support

An example of a Health Experience Wheel is included in Appendix 4.

FINDINGS

The findings are described in this report as they relate to CHF indicators of consumer-centred care. The full patient journey life stage stories are not included and Health Experience Wheel representations are available in a supplement on the CCA website https://www.crohnsandcolitis.com.au/ibdqoc/my-ibd-story/.

All stories involved both positive and negative experience points with some predominantly positive, others predominantly negative, and some balanced. The quality indicators used were found to be of variable relevance to IBD stories.

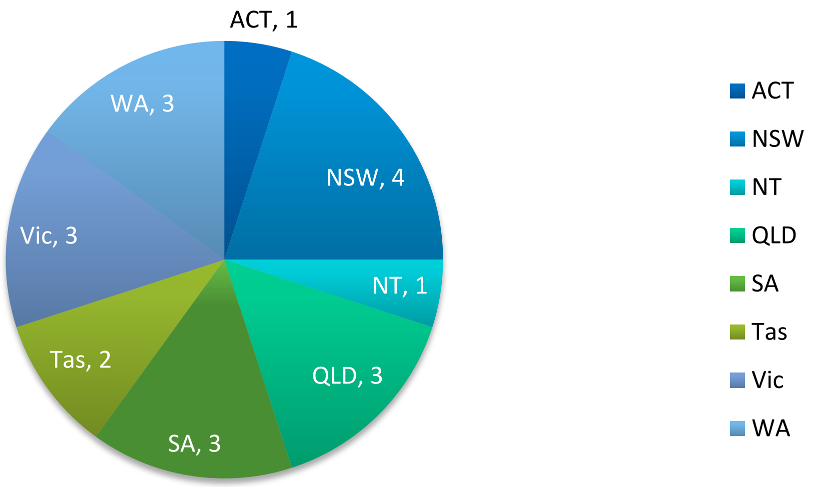
The summary does not aim to compare public and private services, but tries to relay points made about public or private health care that were important enough for the participant to mention.

Participant quotes were not fact-checked and are generally documented including errors of expression. Accordingly statements should be considered participant opinion, not medical fact.

Participation

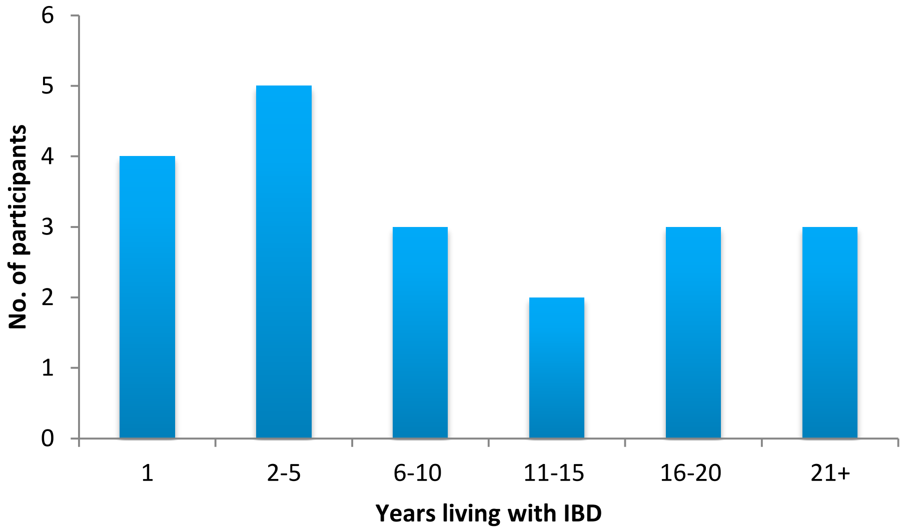
Twenty interviews were reviewed. Five participants were male and 15 female. Ten participants had ulcerative colitis, 9 had Crohn's disease and one identified as having Crohn's colitis. All Australian States and Territories were represented, see Figure 1.

Figure 1 Participants by State



Participants had lived with their condition for between one and 36 years, see Figure 2.

Figure 2 Participant years living with IBD



Some data relates to healthcare at any time over the last 36 years, though the majority of content collected relates to the last ten years. It could be argued that anything before that is irrelevant to today's health care system, but the writer takes the view that even these historical issues present important lessons for today's health care.

1. Access, equity and affordability

Timely access to services for diagnosis, review and treatment varied in both public and private health services. Prompt treatment was often linked with financial cost and inversely linked with rurality of the participant. A range of other costs were described that had a significant impact. For this quality indicator negative issues were more predominant than for any other indicator.

Some participants described good access to a gastroenterologist that led to rapid diagnosis. Examples of this occurred in the community and private hospital. Access to public hospital paediatric admissions and procedures was described as timely. Recurrent presentations at the same emergency department resulted in more rapid or streamlined admissions later in the journey for some.

Conversely, delays to gastroenterologist appointments in the community were reported to have contributed to ongoing severe symptoms and complications such as bowel obstruction.

> *"It took two weeks to get the appointment with the IBD Specialist. I just spent the whole time running from the lounge to toilet. I went from bad to worse. I went to the GP because I couldn't take it anymore and he sent me to hospital. I was admitted for a week and put on high dose steroids IV." [UC13]*

There was a lack of access to specialised gastroenterology services in remote areas via GP and emergency department referral. This contributed to late diagnosis, advanced disease, the need for transfer and complications such as bowel resection:

> *"In 1981 I was teaching in a small town in remote SA and was unwell with abdominal pain and the RFDS visited and thought it might be irritable bowel, so left me in the town. I got worse over a couple of days. I was just vomiting water and the Royal Flying Dentist visited town and took me to Port Augusta hospital. They sent me to a bigger hospital at Whyalla and the same day I had a bowel resection of the terminal ileum and spent the week in hospital."[C5]*

Use of telehealth, Skype, or telephone consultations for specialist medical review or scripts has reduced ongoing travel burden such as long drives (e.g. 3hrs) or expense associated with flights and was described positively.

Surgical treatment in a private hospital was often described as rapid, though one person did wait one month for a colonoscopy. In some cases delayed access to surgery in the public system led to transfer to private hospitals for more rapid access to surgical treatment. This also created significant costs in some cases:

> *"In 2013 I had severe cramping and thought my bowel was obstructed..... I was put on IV antibiotics and they decided I could wait a bit for the surgery. I was supposed to have surgery but it kept getting postponed. I got a price for surgery in a private hospital and went there. The standard of care was great at the Private. I was about $3000 out of pocket." [C21]*

Similar total out of pocket costs were described for private colonoscopy.

Private healthcare and insurance costs were problematic, particularly for low income earners or when long hospitalisations led to reduced income. Limitations within health insurance policies (eg. gastroscopy exclusion) led to diversion of the participant to public healthcare and a delay. Gastroenterologist fees were described as a financial burden with costs of $200 per consultation and only modest Medicare Benefits Schedule (MBS) benefit applicable. Bulk billing by specialists occurred in some cases.

Pharmaceutical Benefits Scheme (PBS) listing of drugs and free access to drugs through pharmaceutical companies was described as an important benefit. Despite the PBS subsidy, the mounting cost of multiple PBS scripts was significant (hundreds of dollars per month) for some, including wage earners, who are generally not entitled to concession status. Access to medications not listed on PBS led to very high cost for participants (e.g. $3000 for two treatments) or was a barrier to access. The application process delays for restricted medications, such as increasingly common biologics, led to prolonged significant symptoms:

> *“.....but over the 3 month waiting time for the new drug I was in dreadful pain, had frequent need of the toilet and spent most of the time housebound rotating from my bed, to the chair out back, to the loo – more from the ‘feeling' or pressure of urgency than the need to go, but I couldn't take the risk, I couldn't even make it into the garden.”[C10]*

In addition, the requirement to meet clinical criteria to be eligible for PBS subsidy of high cost drugs and inadequate communication thereof created anxiety about ongoing secure access to these drugs for one individual.

Other significant costs reported were: GP fees, travel to appointments, parking fees, medications, calprotectin tests, private emergency departments, insurance excess fees, personal training and fees for allied health (multidisciplinary care).

Delays to booking an outpatient appointment occurred, sometimes due to administrative problems. A criticism of public outpatient care was that it was difficult to maintain continuity with the same doctor. Predictably long waiting times at outpatient appointments was described multiple times:

> *“I go to the hospital clinic every couple of months which is about 40 minutes away. The problem is waiting there for the appointments. It could take four hours and the parking is expensive. I can't take a bus there because I might need to use a toilet urgently.”[UC16]*
> *One person suggested that greater resources to outpatient services could reduce delays and possibly result in fewer acute admissions.*

Lack of access to GPs with a skillset including IBD was problematic. Some people had to change GPs and others, particularly in rural areas, had no choice.

It was also noted that the requirement to get a gastroenterologist referral from a GP annually for MBS reimbursement was considered unnecessary for someone being treated for a chronic condition. CCA is aware that the GP can write an indefinite referral but many choose not to, and that gastroenterologists encourage patients to maintain a GP relationship for their general health.

2. Information and understanding

Lack of pre-diagnosis awareness and understanding of IBD was a common starting point for interviews. A range of good and bad experiences of health education, information and understanding were described. Experiences of good quality, targeted information provision were appreciated and used as a tool to for self-management.

General awareness in the community and among undiagnosed individuals about IBD was described as low and was linked with late diagnosis by some:

> *"Maybe I should have got the abdominal pain that I had when I was a teen investigated. I told my parents, but that's all. I'm not sure they could have identified the problem back then."[UC12]*

This awareness gap may have had a role in symptoms being attributed by participants to the following alternative conditions: bowel cancer, migrating contraceptive implant, change in diet, dietary intolerance, or change in climate after relocation.

A lack of information for participants in the period between referral to specialist and diagnosis was identified. This period is a time when symptoms can be unfamiliar and severe.

Information provided by the gastroenterologist immediately after diagnosis by colonoscopy varied. Sometimes it was inadequate, delivered only verbally by nurses, or sought by family. There was a lack of warning about the immediate impact of steroids, in particular psychological effects. This resulted in participants experiencing unacceptable side effects for longer than necessary. There was also a lack of information about the potential side effects of long term use of steroids.

> *"I was started on a high dose of prednisolone..... That absolutely ruined my life. I couldn't sleep, I was starving hungry all the time, dry eyes and dry mouth, and I had panic attacks. I was also on Panadol and a bit of Endone, for pain relief. I told the Gastro about the side effects and he said I should've contacted him. It's hard to get through to the outpatient clinic. You have to be put through about four transfers. I didn't know what to expect." [C6]*

There was also a lack of information at diagnosis about: the psychological impact of IBD, what to expect if a flare occurred, lifestyle, cure, deterioration and fertility.

The adjustment of information level for a paediatrics was thought to be appropriate and understandable by a participant. Information was also provided to family members of participants not feeling well enough to receive information, which was appreciated. An example of good information at diagnosis involved verbal and printed information, contact details for a nurse and follow up details.

Some gastroenterologists provided very good information on the diagnosis and treatments. Participants reported that, in particular, information that the condition was readily treatable was reassuring:

> *"The specialist was very motivated and put me at ease that this could be managed. Her response was that there was a range of choices for treatment and that we would keep going until we found one that worked for me. That kind of individualised care was very reassuring. It was important because on steroids you never think straight and are a ball of emotions, so it was good to have someone leading treatment who could communicate clearly and offer treatment solutions."[UC13]*

Use of email or telephone consultations with the gastroenterologist improved awareness and understanding about treatments for participants particularly those living in a remote region.

Information provided by the treating team to a participant was good prior to significant surgery (ileostomy) and support informed decision making.

Where gastroenterologists failed to provide good information, this led to the participant changing to a different gastroenterologist in some cases. The change resulted in better information for these participants, but there was also acknowledgement that participant skills in asking questions had improved. Good information and explanation by gastroenterologists was highly regarded.

Some gastroenterologists were described as poor communicators and some services didn't provide enough information, prompting participants to seek information elsewhere including family, workplace and friends. One participant commented that the medical language used to describe colonoscopy results needed to be better explained. Nevertheless that participant regarded the gastroenterologist highly:

> *"The gastroenterologist is really good, straight forward, he's honest, but could use simpler language. He's sympathetic. Sometimes he gives me medications and doesn't explain it clearly so I have to ask him to explain it." [UC17]*

Lack of information, understanding and monitoring precipitated reactive care:

> *"One problem is that the care is reactive rather than proactive. Maybe someone should check in now and then. It's my own fault, I wait to get symptoms before I do anything. I've never had an IBD nurse. I wasn't given any information on support, fact sheets or brochures pretty much." [UC20]*

Multidisciplinary teams and IBD nurses provided a broad range of information that was good quality, timely, and well-pitched in terms of appropriate detail. One participant remarked that they don't always get their doctor responding to queries, but someone from the IBD team (IBD nurse or registrar) calls quickly. IBD nurses coordinated with GPs and prevented the need for specialist visits in some cases. Provision of pregnancy related information successfully allayed fears of treatment effects during pregnancy and breastfeeding. However there was a gap in information on IBD skilled obstetricians requiring a participant to locate a suitable clinician through informal networks.

Dietitian advice was described by one participant as general, not individualised and as a result not helpful.

A gap in information was identified when treating specialists are absent, because junior doctors provide minimal information and IBD nurses seldom visit the inpatient setting.

Other information problems included: lack of information about multidisciplinary care or treatment plan in the 1990's, lack of information available for students and teachers and misinformation on United States sourced printed material. Participants also described receiving poor information from GPs, and complementary therapists with one providing information on irritable bowel syndrome rather than IBD.

Information on the internet was described as lacking in the past but improving more recently. Some participants described difficulty in knowing which information to trust on the web, and felt that maybe things weren't explained as thoroughly as they could be by clinicians due to a presumption that participants could use the internet to find information. Some gastroenterologists or IBD teams provided information on trusted websites. Participants drew emotional support from Facebook groups. Also Facebook groups/forums provided information on other issues such as new drugs and treatments and volunteering. Patient organisations were also identified as a good source of information.

3. Informed consent (including informed financial consent)

Issues of informed consent were rarely raised by participants.

In one case a participant did not receive adequate explanation about the reason for, and benefit of, a physical examination and subsequently refused consent:

> *"At one stage, after I was diagnosed, a doctor who thought I had gastro, wanted to do an internal examination on my bum. She didn't explain to me why she wanted to do it or how it would help, so I refused." [CD6]*

One participant described his gastroenterologist's efforts to keep him informed about treatment choices by providing him with printed material and discussion. The discussion of treatment involved the advantages and disadvantages, and subsequently a decision was made by the participant.

4. Appropriate care

More issues of appropriate care were raised in interviews than any other quality indicator. Both positive and negative experiences were commonly described. Comments have been grouped as they relate to delayed diagnosis, positive experience of gastroenterologist service, negative experience of gastroenterologist service, multidisciplinary treatment, and hospitalisation and treatment.

Diagnosis

Delay to diagnosis was commonly identified as a negative issue for a range of reasons. This was often during the 'seeking assistance' stage and involved the GP or emergency department. Some participants reported that a range of investigative actions were undertaken that seemed reasonable to them, whilst others reported being dismissed as having a minor problem or other diagnosis that wasn't correct, e.g. eating disorder. Some cases involved delayed referral to a gastroenterologist:

> *"It took them a long time to diagnose me, maybe up to a year of consistent diarrhoea, gut pain and not wanting to eat. After a long while my GP told my Dad I was either gay or had mental problems. Dad got angry and asked me what was wrong with me, and I said tummy pain. He took me to a gastroenterologist and I was diagnosed [with Crohn's] the next day."[C2]*

In another example, a participant's immediate needs were addressed in in an emergency department but specialist referral did not seem to be actioned:

> *"The staff at the emergency department were very nice and helped with the pain, but the problem was that there was no follow up. So I guess I was misdiagnosed because when they did find out, it [Crohn's disease] was quite advanced. I hadn't seen a specialist in the Pilbara."[C9]*

Inconsistent advice from an emergency department and GP about results led to a delay in diagnosis during which time the participant was not eating during the day at work. Other impacts of delay to diagnosis included:

- Mental health impacts
- Job uncertainty
- Limited ability to continue positive behaviours such as exercise

There were other cases where participants praised their GP for rapid referral to a gastroenterologist when they presented with symptoms. A paediatrician initiated prompt referral to gastroenterologist and similarly a paediatric specialist hospital diagnosed the condition rapidly.

One participant described trying a range of complementary therapies before diagnosis without good effect.

Positive experience of gastroenterologist

Participants often described excellent service from their gastroenterologist. These comments related to empathy, responsiveness, clinical outcomes, planning and involvement of the participant. The empathy shown by a gastroenterologist was important:

> *"I've had the same GP and Gastro which has been good. My gastroenterologist has been very supportive and had a lot of empathy. That's why I've stuck with him. He's not just factual. Some of the surgeons were just factual and that probably put me off a little." [UC19]*

The flexibility of a gastroenterologist to answer queries rapidly and participate in telephone or email communication was very helpful for remote participants and avoided a three day travel turnaround for one participant. Consistent review by one gastroenterologist was thought to support rapid public hospital admission.

A number of participants attributed good clinical outcomes to their gastroenterologist. These outcomes included rapid diagnosis, appropriate medication changes and dose escalation and initiation of biological treatments that effectively controlled disease.

A number of participants described persistent fatigue. This was variably accepted as reasonable by some health professionals and unacceptable requiring a change of management by others. Validation of this symptom and having it addressed by a gastroenterologist was very significant for one participant:

> *"The fact that he acknowledged and recognised my fatigue as a symptom was huge for me. When my Mum would ask how I was, I would say "tired" and she would be angry at me because I all I was saying was that I was tired. When the new specialist asked about my fatigue and wanted to improve it, it was a huge piece in the puzzle for me and everybody else. They all got it after that." [UC11]*

Having a gastroenterologist who was also a researcher promoted the participant's confidence that their treatment was frontline for one participant.

Good planning and involvement of the participant has led to understanding of the anticipated course of early disease, a clear plan of what to do when symptoms increase, confidence that the condition is treatable and optimism that other novel drugs will be available in the future if required.

Negative experience of gastroenterologist

Negative experiences of gastroenterologist service usually related to the participant attributing a poor outcome to an act of omission by a gastroenterologist.

Failure to provide an action plan to participant meant that severe side effects of medication were not managed as participant did not know where to go to get help and struggled with the Outpatient contact barriers.

A number of participants reported continuing on unchanged treatments despite escalating symptoms or persistent significant symptoms for extended periods up to years:

> *"After six months of treatment things started to come undone and the drugs weren't as effective so the doses were increased. I was a bit frustrated with the specialist. This continued for a few years. I did my own research and I brought up Infliximab with him. It was annoying that he didn't suggest it to me. He referred me to someone who does more of this type of treatment." [UC14]*

In one case a gastroenterologist treated the participant for other diagnoses without resolution for 2-3 years before diagnosing Crohn's disease, though it is not clear whether these diagnoses were correct or not.

A delay of six weeks to usual gastroenterologist appointment for a symptomatic participant had significant impact and demonstrates the effect of not having the right care at the right time:

> *"Then 12 months later I got symptoms of an obstruction but couldn't see my gastroenterologist for 6 weeks because he was so busy. I went to a public ED and they couldn't find an obstruction. I went back again and they tried to give me a suppository, but I didn't have a rectum after the ileostomy. So my husband put his foot down and got me transferred to the private. I did have an obstruction and was operated on that night. Then I had a bowel perforation and was in hospital for three months. I was very sick and had a large open wound at the surgery site. I was on TPN, then naso-gastric feeds." [C3]*

Multidisciplinary treatment

Where there was access to multidisciplinary team this was generally a positive experience. Lack of access to multidisciplinary care was a problem and occasionally the experience of care by a health professional was unsatisfactory.

Being engaged with an IBD team gave one participant access to IBD nurses, dietitian, psychologist and multidisciplinary team meetings where their case was discussed. Some IBD services provided timely advice by email. It was noted that IBD nurses rarely visited the participant in the inpatient setting and although the ward nurses were great, they did not have the time to provide similar discussion to the IBD nurses.

Multidisciplinary care was not offered to all participants:

> *"I've never been offered allied health support. A dietitian or nutritionist may have been useful, but from a psychology point of view I have never had much of a problem and never felt the need to speak to someone." [UC11]*

Another participant spoke of being referred to a dietitian whilst in hospital, eight years after diagnosis.

Dietitian provision of very broad, general advice was described as unhelpful and more specific individualised care as useful.

There was a case in which a pharmacist in a small town gave poor medication advice about using non-steroidal anti-inflammatory drugs that embodies other comments that generalist health professionals had inadequate knowledge of IBD. This included GPs and resulted in participants seeking new GP's:

> *"I've seen a few GP doctors that I've left behind because they knew so little about Crohn's."[C7]*

Participants experienced other benefits and problems during hospitalisation or ongoing treatment that appear to have system based or multiple causes.

Some of the benefits included:

- Having treatment consistently at a single hospital resulted in continuity benefits such as rapid admission, staff IBD skillset and knowledge of the participant's care.
- Paediatric hospital care seemed to be specialised and of high quality and the use total liquid diet for a participant was effective.
- A major metropolitan hospital was able to diagnose rapidly after transfer from regional hospital. A similar experience was described at a private hospital after unsatisfactory attendance at a public hospital.
- A private hospital provided excellent standard of care during bowel resection admission.
- Infusion care delivered in a local oncology department avoided significant travel and provides a standard of care regarded highly by the participant due to the quality of nurses.
- A surgeon who did colonoscopy commenced ulcerative colitis treatment immediately, before gastroenterology review which was appreciated by participant.
- An accessible gastroenterologist at a public outpatient clinic has facilitated effective changes in medication and treatment.
- Care provided by the Royal Flying Doctor Service was generally highly regarded.

Some of the systematic problems that occurred include:

- More than one participant who attended an emergency department (after diagnosis) felt the extent of symptoms was not believed which had a significant impact. One was sent home with inadequate symptom management i.e. oral medication rather than intravenous for a vomiting participant.
- A participant with Crohn's disease with significant weight loss and loss of appetite felt she was not being understood but rather was being investigated for anorexia and the only goal was weight gain.

- Infusions delivered in the inpatient ward were prolonged compared to the day patient setting and resulted in long admissions of up to 14 hours due to different processes.
- A participant with symptoms for years and clear colonoscopies required a hemicolectomy before a biopsy from the operative site confirmed diagnosis.
- A participant required multiple bowel preparations due to cancellations of colonoscopy due to lack of resources. In general colonoscopy was described as a very unpleasant experience, but in this case it also would have nutritional impact.
- Location of a teenager restricted to only intravenous nutrition for three months in a shared room with people eating food was difficult for the participant.
- Treatment of participant in a large hospital but outside of the gastroenterology ward made her feel low priority.
- Lack of monitoring made participant feel like care was reactive.

Long term use of steroids had a detrimental impact on a participant:

> *"When I got to my sweet spot with medication I was symptom free for a couple of years, but then I started to flare regularly, at least three times per year. The GP commenced steroids which solved the ulcerative colitis problem, but then I had problems from the steroids. They changed my mental health, I gained lots of weight through fluid and I had issues with sleeping. I've been off and on steroids ever since. The longest period I was on steroids was two years. Other times it was 6 months. If they weaned me off quickly I would flare. Then they realised Salazopyrin alone was not working for me." [UC15]*

This case occurred despite the participant raising the problem of long term steroids with her gastroenterologist. This event occurred around 2007. The problem of over-use of steroids was only resolved when the participant reached a crisis in health, changed GP who advised her to get a new gastroenterologist. This case was not isolated, with another example of a gastroenterologist seemingly dismissing concerns about severe steroid side effects.

In general, medication side effects were commented on frequently and these experiences were described as good or bad depending on whether there was a system in place to promptly action a change for the participant.

5. Respectful care

A small number of issues were identified that relate to the respectful care.

As mentioned in relation to *4. Appropriate care*, a couple of participants felt their description of the severity of symptoms was not believed by doctors in an emergency department. One lost confidence to act on symptoms as a result:

> *"On one occasion, I went to the emergency room at 5am really sick. I got the impression that the doctor didn't really believe me and that was the biggest knock back to my confidence that I've had. Now I don't go to the emergency room until I am desperate."[C4]*

Preservation of dignity was inadequate in one case:

> *"At the rooms before my first colonoscopy they made me wait for ages. They asked me go into a tiny room with a bed and a calico sheet and told me to pull my pants down past my knees and leave my shoes on and lie on the bed. I was there for 20 minutes and I felt humiliated and started crying which is very unusual for me." [C6]*

Similarly, the presence of too many doctors during the examination of a participant experiencing her first flare was perceived as inappropriate by the participant.

Conversely, participants felt health professional's display of empathy was important to them:

> *"My specialist sees me every six months and I have the infusions through an oncology unit locally. The nurses in Oncology are empathetic. It's an invisible disease that people just don't understand. So their empathy and willingness to help is as important to me as the treatment itself." [UC14]*

One participant described the gastroenterologists empathy as the reason she had continued to see him.

6. Whole of person care

For some people aspects of their health outside of the gut were not well managed. Generally involvement of members of the broader multidisciplinary team helped with these issues. GPs played an important role in this type of referral.

A prolonged period to diagnosis with little support had a clear mental health impact for one participant:

> *"Sometimes I thought I would get to the bottom of this whatever it took and other times I'd have to cancel client meetings because I was home in bed unable to move. I thought I'm going to lose my job, and how will I survive. I was unable to go running, which is very important to me. All of this had an impact on depression and anxiety. There was a feeling of helplessness a great deal of the time." [UC14]*

Probable misdiagnosis of eating disorders or mental health problems was frustrating for several young participants. Others were not advised of the emotional impact that the diagnosis and commencement on prednisolone could have on them.

The location of a teenager on months of TPN in a hospital room with people eating, while perhaps unresolvable with resources at hand, is an example of the limitation of achieving whole of person care currently.

Positive whole of person care practice included:

- GP management plans with referral to psychology and dietetics
- Counselling and assurance by a gastroenterologist about novel treatment development
- Compassionate infusion nurses
- Provision of psychology service to overcome anxiety related to bowel action urgency
- Provision of psychology to manage isolation and fears about relationships associated with IBD
- GP coordination of sports medicine and gastroenterology management

Online support groups were described as a useful resource for emotional support but also as being too full of personal detail and negativity for others.

7. Coordinated care and supported transitions

Transition from paediatric to adult care is common in IBD care due to the young onset of the conditions and ongoing nature. The couple of experiences of transitional care from paediatric to adult care raised were positive:

> *"I transitioned from paediatric to adult, that was really good. I saw both of them over the same period and they made sure nothing got missed and that I liked the doctor. They worked at the same hospital." [C8]*

There were also good examples of coordination between gastroenterologists, other specialists, GPs, IBD nurses and IBD teams: "they are constantly talking to each other".

Inconsistency of information about follow up between the GP and emergency department were problematic for one participant:

> *"A week or so later I went to the emergency clinic who organised stool samples and blood tests. I went to my GP the next week, but no-one could give me an indication of what it was. When the stool sample results arrived the emergency clinic wanted me to come in urgently, but the GP seemed to think it wasn't that urgent – it was two different messages and I didn't know who to listen to. I found it extremely frustrating at the time that no doctors would really take it seriously." [UC12]*

8. Safety and quality

A small number of safety and quality issues arose which were negative. While they are not necessarily preventable, they were nevertheless poor experiences or outcomes for the participants. One surgical complication of paralytic ileus was mentioned. A person had multiple bowel cancer screening colonoscopies while symptomatic without diagnosis of IBD. One participant contracted immunosuppressant induced hepatitis which highlights the need for appropriate immunosuppressant monitoring systems. There were cases of prolonged steroid use resulting in persistent and severe side effects. In one case participant concerns about this were dismissed.

9. Control and choice

Control and choice was positively viewed by those who described it. The omission of control of choice was problematic.

One participant described being able to have input into her date for surgery:

> *"In 2006 they decided that my fistulas and abscesses could not be fixed and I needed an ileostomy. They agreed to let me wait until after my uni exams. I was only in hospital for 10 days. The education around that was much better. The stomal nurse was very good. There was no IBD nurse there." [C3]*

One participant described control over treatments prescribed:

> *"My gastroenterologist in NSW was very good. I'm big on researching what's going on with Crohn's on the web. With every medication I was put on, there was always a conversation about the pros and cons, he never told me "you have to do this"."[C7]*

There were a number of participants who were frustrated with their symptoms or treatment side effects and were not able to effect change in collaboration with their treating doctor. A participant described significant side effects of steroids and rather than discuss different treatment options she was told she needed them to get better. Other references such as "I'm the specialist here" demonstrate the challenge for participants achieving control of their health care in a position that is often perceived as subordinate to the health professional.

10. Social, economic and community participation

Travel insurance was a problem which presents a financial risk for people with IBD travelling. Welfare payments were inflexible in the case of one person with IBD and comorbidities:

> *"At the time of diagnosis my marriage broke down and I ended up on Newstart. I had a medical certificate for a while so I didn't have to seek work, but also wasn't eligible to study."[UC18]*

11. Carers and support

Participants commonly spoke about their relationships but rarely about aspects that related to their healthcare. Many described supportive immediate family, or alternatively family that understood the significance of the illness once a flare or significant hospitalisation occurred.

> *"I'm lucky I have a supportive family. They help me cover costs and understand what I'm going through." [C4]*

Some raised a lack of family or carer understanding of the conditions early in their illness, this was not particularly problematic, but does appear to be a gap in educational and information processes.

In one case there was an ongoing lack of support and family understanding:

> *"There are no local support groups here, only in the city and the IBD phone support in Perth just did not work for me. Talking to friends and family is also difficult. I don't think they read up on Crohn's so don't understand it, then keep asking me if I'm better, or if the new medication has solved all my problems. They don't want to hear about my trials and tribulations, which seem to be ongoing and constantly changing."[C10]*

Summary issues table

The following table provides a list of issues identified in the findings that could be further examined in future larger scale survey.

Table 1

CHF indicators of consumer-centred care	Issues
Access, equity and affordability	a) Time from seeking assistance to diagnosis b) Access to gastroenterologist for diagnosis (including remoteness) c) Differences in access to surgery in public and private hospitals d) Costs associated with care and impact thereof : health professionals, medication, travel & investigations e) Access to informed GPs
Information and understanding	f) General awareness of IBD in the community g) Quality of information at diagnosis including emergency plan and steroid use h) Who provides information and quality thereof including dietitians and pharmacists i) Awareness of reliable web based information
Informed consent	j) Understanding of, and choice in, options for treatment
Appropriate care	k) Emergency department experience: assessment, action and plan l) Impact of complementary therapies m) Gastroenterologist response to problematic symptoms n) Responsiveness of system to patient deterioration o) Access to multidisciplinary team p) Use of communication methods: face to face, email, and video q) Continuity of service r) Experience of steroid use and monitoring s) Health professional response to poor medication tolerance t) Level of empathy shown by health professionals i.e. gastroenterologists
Respectful care	u) Was care respectful and preserved dignity
Whole of person care	v) Access to psychological care
Coordinated care and supported transitions	w) Sharing of information between GP emergency departments and specialist services x) Transitional care experience
Safety and quality	y) Experience of incidents, errors and their impact
Control and choice	z) Involvement in decisions on treatment
Carers and support	aa) Identify support level and information for carers

CONCLUSION

It is inherently of interest that over 50 people living with IBD put their hand up to participate in just 20 places to share important and personal information for the purpose of improving the quality of IBD care in Australia. All had some positive comments about their healthcare even if they experienced a predominantly negative journey with serious illness during acute episodes, or unresolved symptoms throughout their journey. Significantly, many experiences were described that fell short of the CHF patient quality indicators.

There was inequity of access to care and the costs associated with care. Delays in access to specialised services were common, particularly in rural areas. This is of particular importance given the effective role of specialist services in diagnosis that was described. Private hospitals provided some benefits in rapid access, particularly for surgery, but costs associated with this were significant and in some cases prohibitive. Other costs were a significant burden including: medical fees, insurance, medication, calprotectin tests and allied health services. Consumer cost reduction due to PBS listing of drugs was important to participants.

When participants had a lack of information in the pre-diagnosis stage, after diagnosis or in early treatment the impact often resulted in physical suffering or mental anguish for participants. Some gastroenterologists provided high quality, timely information using face to face consultation and other means, which was greatly appreciated by participants and resulted in client loyalty. Multidisciplinary teams and IBD nurses provided good, accessible information. Internet and social media information was a popular source of information, but was variable.

Appropriate care was not delivered at times in many participants experience, in fact almost all. Yet when it was, participants were grateful and complimentary about what it meant for them. Diagnosis was not timely for a variety of reasons, including delay to gastroenterologist referral by GP or emergency department. Then, diagnosis was generally fairly rapid once the gastroenterologist was involved.

Gastroenterologist traits that were positively viewed were empathy, responsiveness, effective clinical outcome, involvement of participant in care and planning for deterioration. Where these traits were perceived as lacking, participants often attributed significant persistent or escalating symptoms directly to their management. Multidisciplinary care through specialised IBD teams was well regarded where present, but often not available. Ad hoc consultations with GPs and other health professionals were often variable with a lack of knowledge about IBD management evident.

A range of treatment and hospital related problems occurred to participants, though the impact of short and long term use of steroids was particularly fraught.

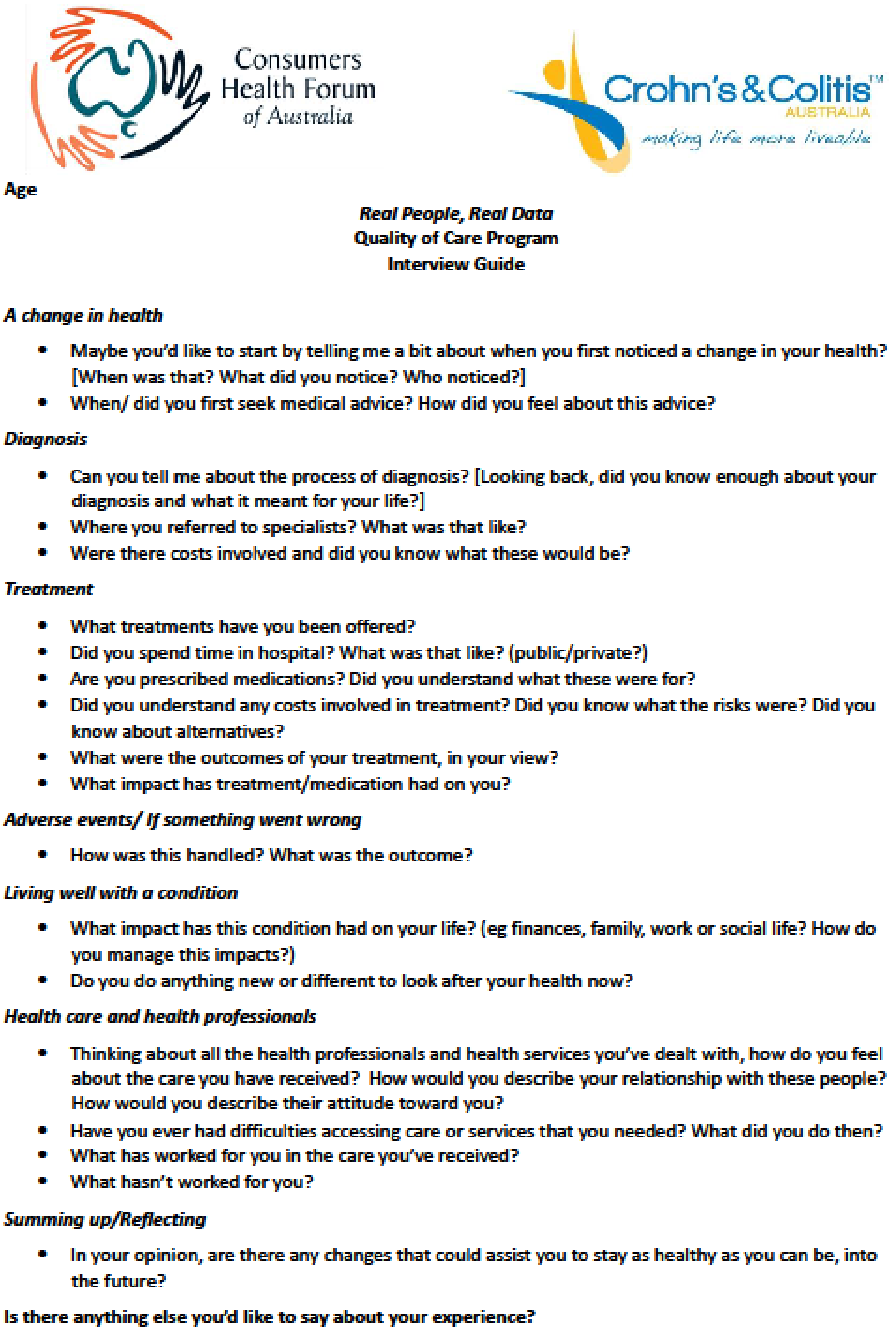
Problems with respectful care arose in relation to ill participants having symptoms dismissed or disbelieved which had a significant impact on psychological and health care seeking behaviour. Participants identified aspects of their healthcare and psychosocial journey that required attention outside of their gut health. Good GP or gastroenterologist management or referral to psychologists and other health professionals for 'non-gut' healthcare was effective.

Unfortunately some participants had little or no attention to the impact of the gut disease on other important aspects of the health.

A few participants made specific mention of how they had input into their care decisions and been able to directly influence that care, and where this was not the case it led to frustration and most likely unnecessary suffering.

The CHF Patient Life Journey interview format was effective at guiding stories that were adequately detailed and focussed on health care. The Health Experience Wheel is a useful representation of positive and negative issues in a single participant's story. It has limitations when multiple stories are considered and requires additional processes to aggregate information about individual quality indicators or journey phases. The processes undertaken have identified issues of IBD care from the perspective of those living with IBD and will provide information for practical use in quality improvement and design of future surveys.

Appendix 1: Interview guide



Age

Real People, Real Data
Quality of Care Program
Interview Guide

A change in health

- Maybe you'd like to start by telling me a bit about when you first noticed a change in your health? [When was that? What did you notice? Who noticed?]
- When/ did you first seek medical advice? How did you feel about this advice?

Diagnosis

- Can you tell me about the process of diagnosis? [Looking back, did you know enough about your diagnosis and what it meant for your life?]
- Where you referred to specialists? What was that like?
- Were there costs involved and did you know what these would be?

Treatment

- What treatments have you been offered?
- Did you spend time in hospital? What was that like? (public/private?)
- Are you prescribed medications? Did you understand what these were for?
- Did you understand any costs involved in treatment? Did you know what the risks were? Did you know about alternatives?
- What were the outcomes of your treatment, in your view?
- What impact has treatment/medication had on you?

Adverse events/ If something went wrong

- How was this handled? What was the outcome?

Living well with a condition

- What impact has this condition had on your life? (eg finances, family, work or social life? How do you manage this impacts?)
- Do you do anything new or different to look after your health now?

Health care and health professionals

- Thinking about all the health professionals and health services you've dealt with, how do you feel about the care you have received? How would you describe your relationship with these people? How would you describe their attitude toward you?
- Have you ever had difficulties accessing care or services that you needed? What did you do then?
- What has worked for you in the care you've received?
- What hasn't worked for you?

Summing up/Reflecting

- In your opinion, are there any changes that could assist you to stay as healthy as you can be, into the future?

Is there anything else you'd like to say about your experience?

Appendix 2: Patient life journey transcript

My IBD Story

Interview record

Interviewee: C21

Age: 28, male

A change in health

I had symptoms very early in my life but nobody knew what it was.

Seeking assistance

I saw a few GPs but they thought it was a bug or a virus. Nobody knew what it was and I don't think as much was known about Crohn's then.

Diagnosis

In Year 8 I was referred to a Sydney Children's Hospital and had a colonoscopy and got the diagnosis of Crohn's. It was a bittersweet moment because we didn't know anything about Crohn's. I was 12 years old.

At the Children's they dumb down the information so you can understand it. I felt strange as a young male going through puberty talking about my poo and toilet. But I understood what they were getting at when they tried to tell me about Crohn's.

Treatment

I had to go on Osmolite and couldn't have food for about three months. And because I was at school in year eight I had to take the drink with me and all the other kids would be asking why I had to have it. Then we did a process of elimination to see what food was affecting my Crohn's.

Then I was good for a few years on Sulfasalazine.

In year 11 I had a flare and developed a fistula. I would go to the toilet and either wee bubbles or wee blood. I had to go on TPN with no food and missed 3 months of VCE. That time it was easier for me to understand things, but it was hard to be in a room with other younger kids who were eating. You could smell the food.

I had to transition to an adult hospital and I've been seeing a doctor who is a professor for about 10 years now. The transition went well. Being a bit older I understood it.

The things I didn't like were the long waits at appointments and seeing a registrar instead of the professor. I always like to see the same doctor. Every year I have a colonoscopy and they have to stretch my bowel to open strictures.

In 2013 I had severe cramping and though my bowel was obstructed. The GP said there was nothing he could do for me so I emailed the professor who said come to hospital and I'll see you in Emergency. I saw him within 20 minutes. I was put on IV antibiotics and they decided I could wait a bit for the surgery. I was supposed to have surgery but it kept getting postponed. I got a price for surgery in a private hospital and went there. The standard of care was great at the Private. I was about $3000 out of pocket.

I was in and out of hospital a bit over the next few years. When they saw me at the public emergency department they knew me and I was straight in which was good. The nurses were fantastic.

Life with a health issue

Things at the moment are good, manageable. I work full time. I have been married for about three years and have a newborn son.

I have been working as a police officer for about 8 years. I joined the cops with Crohn's. I needed to get a clearance from the doctor to get into the police, but that was fine. I've have had a few complications along the way with my condition and work, but work has been very understanding and accommodating.

I had a colonoscopy a couple months ago and the Crohn's is still at bay. I'm on Questran Lite and Imuran.

I did see a psychologist after my surgery because I was very anxious about leaving the house. That was very helpful, it gave me strategies to manage the worry. Not many people know the psychological effect of the Crohn's causing anxiety.

If I'm going out to the city I make sure I go to the toilet a few times beforehand and might take Gastro-Stop. Usually I'm fine but I've missed a few functions, say when I'm bleeding or the Gastro-Stop isn't working.

I've put on a bit of weight lately so I see a personal trainer who advises me on exercise and diet. That's been helpful for being healthier.

Having quick access to your specialist is very important. Being able to use email to communicate with him works well.

Some of the experiences in emergency departments have been poor. When they kept me waiting, postponing the surgery was annoying. It left me in limbo.

Once when I was 25yo I had to share a room with an 80yo who was screaming all night. I know it's a public hospital but they should organise their wards better.

Medication is quite expensive. Because I work full time I don't get any benefits to cover the cost of medication. Cheaper medication would help.

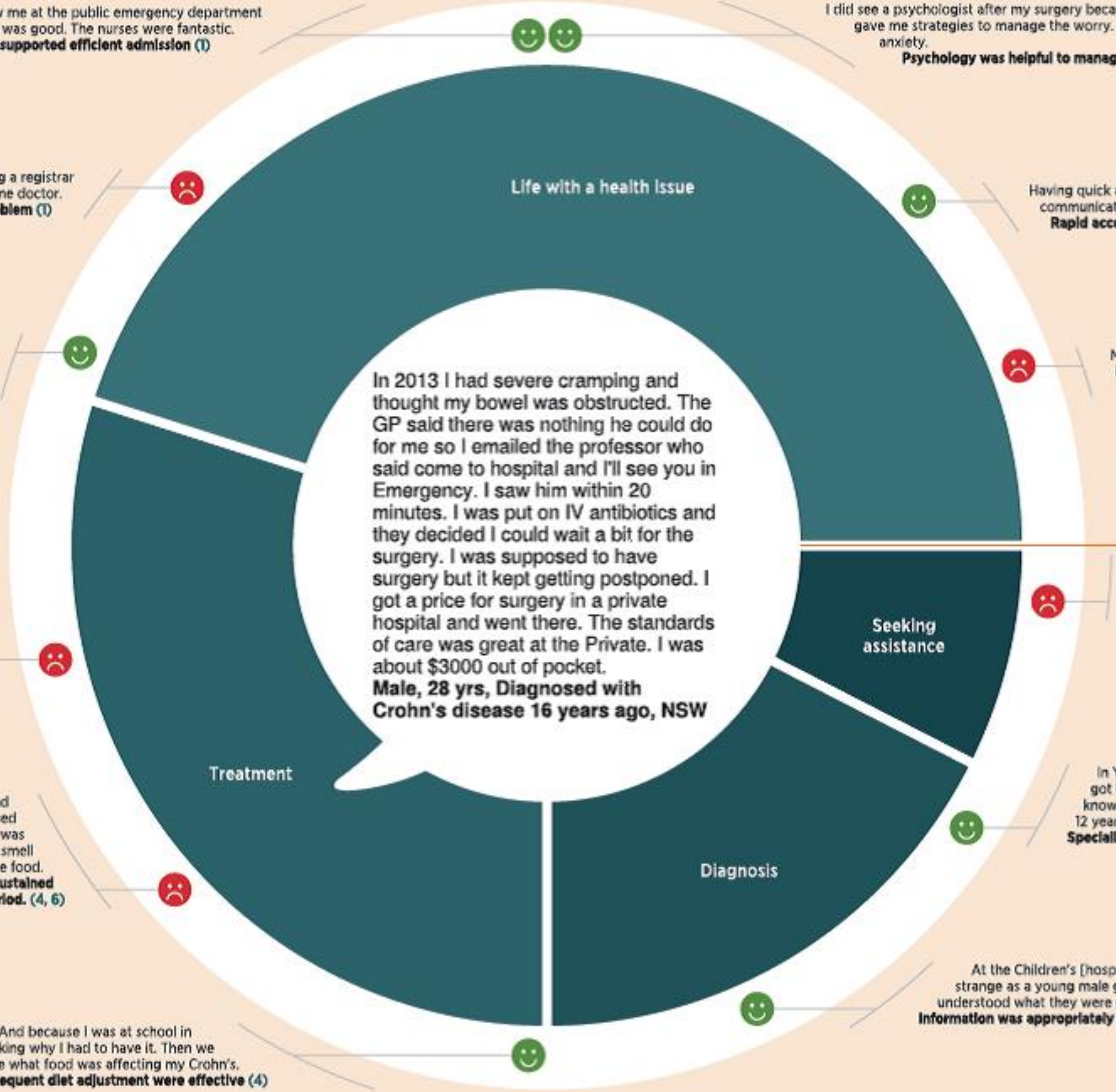
Crohn's has been a bit obstructive in my life but I've tried to overcome it. It didn't stop me becoming a police officer, I just kept working and working towards it.

Appendix 3: CHF quality indicators of consumer-centred care

Criteria	Definition
1. Access, equity and affordability	People can access services to address their healthcare needs and to manage their condition/s. This includes access to safe, quality, timely and appropriate services, treatments, preventative care and health promotion. Healthcare services, professionals and the healthcare system recognise and address dimensions of health inequality such as those related to geographic location, socioeconomic status, language, culture or Indigenous status. People can afford the treatment and care that they require.
2. Information and understanding	People are provided with accurate, relevant and comprehensive information, that considers their individual condition, language, age, understanding, abilities and culture. This healthcare information is open, timely and appropriate and delivered in a way the consumer can understand. This information includes (but is not limited to): discharge information, information about medicines, treatments and devices, danger signs to look out for and clear, comprehensible information for self-care.
3. Informed consent (including informed financial consent)	Patients are provided with all the relevant information to support their agreement (or not) to any medical or health procedure. This involves being informed by their treating professional/s about their options, understanding the benefits and any risks associated with the procedure and being supported by their treating professional(s) to make a decision about their care. Patients are provided with clear, timely and comprehensible information about the cost of treatments and procedures.
4. Appropriate care	Patients receive the right care, at the right place, at the right time, and from the right professional.
5. Respectful care	Patients receive care that demonstrates respect for their culture, beliefs, values and personal characteristics, and for their preferences and expressed needs.
6. Whole of person care	Patients receive care that recognise and responds to their mental, physical and emotional wellbeing.
7. Coordinated care and supported transitions	Patients experience care that is coordinated and integrated of care, with smooth transitions between different services.
8. Safety and quality	Care and treatment do not harm the consumer. Any harms and risks involved in treatment are clearly communicated and understood by the consumer. If an adverse event occurs, this is openly disclosed. Consumers who have not received appropriate care can make complaints and seek restitution through complaints and oversight mechanisms. Healthcare organisations have a culture of openness and transparency around safety and quality, and processes to respond to complaints and

	feedback. Healthcare organisations have a learning culture and processes to support continuous quality improvement.
9. Control and choice	Consumers are involved in self-management of their health and any health conditions. This can involve having the knowledge, skills and confidence to manage one's own health, and having a choice of healthcare provider. Patients have opportunities to be involved in health policy, and take shared responsibility for policy-making through meaningful and supported engagement in all levels and at all points of decision-making.
10. Social, economic and community participation	Consumers receive healthcare that supports their social, economic and community participation – for example studying, training, working and/or taking part in community activities. Consumers have safe, secure housing; freedom from stigma and discrimination; and a sense of connection to culture. These enable and underpin participation and good health.
11. Carers and support	Consumers are supported by family, friends or other carers. Carers, family and friends are supported to care for the patient. Family, friends or other carers should be involved in decision-making and care planning in support of the patient.

Appendix 4: Health Experience Wheel example



In 2013 I had severe cramping and thought my bowel was obstructed. The GP said there was nothing he could do for me so I emailed the professor who said come to hospital and I'll see you in Emergency. I saw him within 20 minutes. I was put on IV antibiotics and they decided I could wait a bit for the surgery. I was supposed to have surgery but it kept getting postponed. I got a price for surgery in a private hospital and went there. The standards of care was great at the Private. I was about $3000 out of pocket.
Male, 28 yrs, Diagnosed with Crohn's disease 16 years ago, NSW

I was in and out of hospital a bit over the next few years. When they saw me at the public emergency department they knew me and I was straight in which was good. The nurses were fantastic.
Recurrent admissions at same Emergency Department supported efficient admission (1)

The things I didn't like were the long waits at appointments and seeing a registrar instead of the professor. I always like to see the same doctor.
Delays at appointments and discontinuity of doctor are a problem (1)

I had to transition to an adult hospital and I've been seeing a doctor who is a professor for about 10 years now. The transition went well. Being a bit older I understood it.
Paediatric to adult transition went well. (7)

In 2013 I had severe cramping and thought my bowel was obstructed. The GP said there was nothing he could do for me so I emailed the professor who said come to hospital and I'll see you in Emergency. I saw him within 20 minutes. I was put on IV antibiotics and they decided I could wait a bit for the surgery. I was supposed to have surgery but it kept getting postponed. I got a price for surgery in a private hospital and went there. The standards of care was great at the Private. I was about $3000 out of pocket.
Delays to surgery at public hospital resulted in expensive private hospital care (1)

In year 11 I had a flare and developed a fistula. I would go to the toilet and either wee bubbles or wee blood. I had to go on TPN with no food and missed 3 months of VCE. That time it was easier for me to understand things, but it was hard to be in a room with other younger kids who were eating. You could smell the food.
Being on a ward with food smells was difficult being nil orally for a sustained period. (4, 6)

I had to go on Osmolyte and couldn't have food for about three months. And because I was at school in year eight I had to take the drink with me and all the other kids would be asking why I had to have it. Then we did a process of elimination to see what food was affecting my Crohn's.
Liquid diet and subsequent diet adjustment were effective (4)

I did see a psychologist after my surgery because I was very anxious about leaving the house. That was very helpful, it gave me strategies to manage the worry. Not many people know the psychological effect of the Crohn's causing anxiety.
Psychology was helpful to manage anxiety (6)

Having quick access to your specialist is very important. Being able to use email to communicate with him works well.
Rapid access to specialist is important (4)

Medication is quite expensive. Because I work full time I don't get any benefits to cover the cost of medication. Cheaper medication would help.
Medication can become expensive without concession status (1)

I had symptoms very early in my life but nobody knew what it was . I saw a few GPs but they thought it was a bug or a virus. Nobody knew what it was and I don't think as much was known about Crohn's then.
Lack of awareness about Crohn's may have delayed diagnosis (4)

In Year 8 I was referred to a Children's hospital and had a colonoscopy and got the diagnosis of Crohn's. It was a bittersweet moment because we didn't know anything about Crohn's [but I was relieved to have a diagnosis]. I was 12 years old.
Specialised service identified diagnosis (4)

At the Children's [hospital] they dumb down the information so you can understand it. I felt strange as a young male going through puberty talking about my poo and toilet [habits]. But I understood what they were getting at when they tried to tell me about Crohn's.
Information was appropriately targeted (2)

Consumer Centred Care

1.	Access, equity and affordability	☹☹☺☹
2.	Information and understanding	☺
4.	Appropriate care	☹☺☺☹☺
6.	Whole of person care	☹☺
7.	Coordinated care and supported transitions	☺

Key issues

- Lack of awareness about Crohn's may have delayed diagnosis
- Being on a ward with food smells was difficult being nil orally for a sustained period.
- Delays at appointments and discontinuity of doctor are a problem
- Delays to surgery at public hospital resulted in expensive private hospital care
- Medication can become expensive without concession status

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