

Normal or diseased? Navigating indeterminate gut behaviour

Christina McKerchar^{A,*} , Lee Thompson^A, Susan Bidwell^A and Aaron Hapuku^B

For full list of author affiliations and declarations see end of paper

*Correspondence to:

Christina McKerchar
Department of Population Health,
University of Otago, Christchurch,
34 Gloucester Street, Christchurch,
New Zealand
Email: christina.mckerchar@otago.ac.nz

Handling Editor:

Felicity Goodyear-Smith

Received: 15 August 2023

Accepted: 10 November 2023

Published: 7 December 2023

Cite this:

McKerchar C *et al.*
Journal of Primary Health Care 2023;
15(4): 350–357.
doi:[10.1071/HC23090](https://doi.org/10.1071/HC23090)

© 2023 The Author(s) (or their
employer(s)). Published by
CSIRO Publishing on behalf of The Royal
New Zealand College of General
Practitioners.

This is an open access article distributed
under the Creative Commons Attribution-
NonCommercial-NoDerivatives 4.0
International License ([CC BY-NC-ND](https://creativecommons.org/licenses/by-nc-nd/4.0/))

OPEN ACCESS

ABSTRACT

Introduction. Delayed diagnosis of gut disease is a continuing problem, variously attributed to a range of patient, doctor, and health system factors. Gut disease often begins with indeterminate gut behaviours that are hard to classify. **Aim.** This study aimed to investigate delayed diagnosis from the point of view of the patient, or prospective patient. How gut and gut disease was understood, what might prompt them to seek care, and their experiences of seeking care. **Methods.** Using a qualitative design, we interviewed 44 people in New Zealand. Thirty-three had a diagnosis of gut disease, and 11 did not, though some of the patients in this latter group had symptoms. **Results.** Some participants had a smooth trajectory from first noticing gut symptoms to diagnosis. However, a subgroup of 22 participants experienced long periods of troublesome gut behaviours without a diagnosis. For this subgroup of 22 participants, we found people struggled to work out what was normal, thus influencing when they sought health care. Once they sought health care, experiences of that care could be frustrating, and achieving a diagnosis protracted. Some who remained undiagnosed felt abandoned, though had developed strategies to self-manage. **Discussion.** Indeterminate gut behaviours remain complex to deal with and it can be difficult for both patients and doctors to assess when a symptom or group of symptoms need further investigation, watchful waiting or the use of other supportive strategies. Effectively communicating with healthcare staff can be a significant problem and there is currently a gap in support for patients in this regard.

Keywords: patient journey, primary health care, qualitative trials.

Introduction

Gut diseases such as bowel cancer, coeliac disease, inflammatory bowel disease, and irritable bowel syndrome have better outcomes if they are diagnosed and treated early.^{1–4} Diagnostic delay persists with the underlying causes attributed to a variety of patient, doctor, and health system factors,^{5–7} including difficulties in understanding normal gut function and when normal variation becomes disordered.

Normal gut function appears to be ill defined, contributing to the problem of distinguishing the abnormal.^{8–11} Studies of gut function in healthy people are dominated by a focus on bowel motion frequency and stool consistency. The review by Heitmann *et al.*¹² concluded that normal bowel motion frequency varies between three per day and three per week in both sexes and that stool consistency ranges between type 2 and type 6 on the Bristol Stool Chart.

There are validated instruments for assessing troublesome but not alarming ‘gastro-intestinal complaints’,^{13–15} but considerable difficulty persists in determining where they fall on the spectrum between normality and disease. Stomach rumbling, for example, is part of normal digestion, but frequent and ‘excessive’ noises might indicate a more serious problem.¹⁶ Bloating and abdominal distension can be transient discomforts, yet Lacy *et al.*¹⁷ estimated that chronic, troublesome bloating that has an impact on everyday life affects up to one-third of the general population. Abdominal cramping and pain are also common in general populations, but are similarly difficult to define and diagnose.^{18–20} Moreover, patient information resources tend to be focused around specific

WHAT GAP THIS FILLS

What is already known: The South Island of New Zealand has high rates of gut disease such as bowel cancer and coeliac disease, compared to elsewhere in New Zealand. Delayed diagnosis is one contributing factor to poor outcomes from these diseases.

What this study adds: Distinguishing between normal and abnormal gut behaviours can be difficult for lay people. Patients who have long-running gut issues without overtly alarming symptoms find them difficult to articulate, might not be taken seriously when they see a doctor, and are more likely to have a delayed diagnosis.

diseases (eg bowel cancer or Crohn's disease),^{21–23} rather than providing any guidance on when these indeterminate gut behaviours should cause alarm.

This study was designed to investigate how people understand the gut and gut disease, what might prompt them to seek care, and what happened if or when they did. In New Zealand, the general practitioner (GP) is the gatekeeper to specialist investigations. GP visits are part government funded and part patient co-payment. Specific criteria guide GPs as to the particular symptoms that are appropriate to refer to secondary care.²⁴ Patients presenting with indeterminate gut behaviours very often do not fall within these criteria and will not necessarily be referred for investigation or, if they are, the referrals might be declined. Yet, these were precisely the kind of gut behaviours that caused uncertainty among the participants in our study as to whether they were normal. It is, of course, part of the task of biomedicine to determine the distinction between the 'normal' and the pathological. But, when this task is not straightforward or might be contested by lay people, sociological interpretations can be helpful in interpreting how people manage their uncomfortable embodiment. We draw on concepts from the sociology of health and illness to analyse the data produced in the study.

Methods

This was a qualitative study using a constructivist methodology²⁵ that sought to develop new insights into the perspectives of lay members of the public both with and without diagnosed gut disease. A constructivist paradigm assumes that knowledge is socially constructed, and a researcher's goal is to understand the lived experience of the participants from their point of view.²⁵

Participants and recruitment

We recruited a total of 44 people across the South Island/Te Waipounamu using a snowball sampling method.²⁶ Thirty-

three participants had a medical diagnosis of a gastrointestinal disease, including oesophageal and bowel cancers, Crohn's disease, diverticulitis, coeliac disease, irritable bowel syndrome, gastrointestinal reflux, gastritis, and gall bladder disease. Most had been diagnosed within the last 2 years. A local gastroenterologist was involved in the study, as a mentor, and provided contacts with other hospital specialists about the study. We then connected with hospital specialists and nurses, and discussed with them our study aims and requested their support in recruitment. They were then provided with an information sheet about the study and asked to identify any suitable participants who met our criteria, so that we could contact them about possible recruitment. The remainder was identified through community contacts of the researchers and their networks. We also recruited 11 people without a diagnosis of any gut disease through community contacts.

Participants were aged from their late teens to their late 70s and were located across main centres, regional towns and rural areas. Sixteen identified as male, 27 as female and one as non-binary. Sixteen identified as Māori, 27 New Zealand European and one Fiji Indian. Participants were fairly evenly distributed across the second to fifth socioeconomic quintiles, with none in the highest quintile.

Interviews and analysis

All participants were sent an information sheet about the study and gave written consent to participate. We conducted interviews between June and November 2021. All authors carried out interviews, with LT and SB interviewing non-Māori participants, and Māori participants were interviewed by one of the Māori authors, CM and AH, using appropriate Māori-centred processes, and AH specifically interviewed Māori men. All interviewers are experienced qualitative researchers. Most participants were interviewed in person, with a very low number interviewed by Zoom during a period of coronavirus disease 2019 (Covid-19) travel restrictions. Interviews followed a semi-structured guide (Supplementary Appendix S1), asking participants how they understood the gut and gut disease, when they would seek help and their experiences of seeking and receiving care. The constructivist methodology used informed the development of open-ended questions that enabled participants to talk freely and in depth about their experiences with the interviewer. Participants received an NZ \$20 grocery voucher. Ethical approval for the study was received from University of Otago Human Ethics Committee (Health) No. H21/039].

Interviews were audio recorded and transcribed verbatim. We conducted initial coding for content, before refining those codes into themes for further exploration.²⁷ Due to the constructivist methodology used, thematic analysis was inductive, in order to allow the participant voice to emerge in relation to the research question. Data saturation was reached for the theme and sub-themes discussed in the results.

Results

This paper explores in depth one of these themes – living with disordered gut behaviours – among a subgroup of 22 participants with experience of long periods of troublesome gut behaviours without a diagnosis. They included 17 participants who had eventually received a specific diagnosis as well as five who had not been given a diagnosis. This subgroup was chosen for this analysis given their experiences living with disordered gut behaviours. Although this subgroup included some Māori participants, other themes relating to cultural issues specific to Māori, such as feeling ‘brushed off’ by the healthcare system and also healthcare relationships with the ‘mainstream’ health system, are addressed comprehensively in a separate paper.

The three subthemes we discuss here are: (1) understandings of normal and abnormal gut behaviour; (2) care-seeking for indeterminate gut behaviours; and (3) the tension between pursuing medical diagnosis or taking independent coping measures. We do not include any markers to the transcript material out of concern for potentially identifying participants, particularly those in small communities.

Understandings of normal and abnormal gut behaviour

Many of the participants in our study had experienced troublesome gut behaviours. These behaviours could be embarrassing; for example, having to rush to a toilet, or when audible stomach noises caused comments from work colleagues or clients. One participant had been told their stomach sounded as if ‘a band was playing in there’. It was difficult for this participant to know if this was normal or not:

I’m still not educated with what’s wrong with me or what’s normal. I’m not told that a rumbling stomach isn’t normal or that ...lower intestine cramps is normal or not. Should I be terribly worried about that? ... I don’t know what I don’t know... I think it’s OK. It’s been like that all the time, hasn’t it, so why is it not OK? What is normal?

Bloating and abdominal cramps caused the same kind of uncertainty. Some participants maintained that ‘all women bloat’ or thought it was a normal part of ageing. Others realised, in retrospect, they had dismissed symptoms that were signals of something serious. In one case, bloating had been a precursor to a life-threatening condition, which required major surgery:

Because I was losing weight. And on the other hand, putting it on is faster, you know, at the same time I was going overweight. I was bloating.

Although aware that their gut behaviours were different from other people’s, many reported that they had become

normal to them, so that they might put off seeking care for months or even years:

I’ve had bleeding on and off since, I don’t know, I was 20-years’ old maybe ... not much, just, you know, nothing much, not that I was concerned about that and that goes on through my whole life. And I’ve had diarrhoea-ish stools for a long time, but that’s kind of oh that’s normal.

Moreover, it was often easier to delay making the decision to seek help because there were constraints on taking the first step. They reported feeling that their complaints were not serious enough to justify taking up a doctor’s time. Gut problems were also difficult to talk about if they did not have a supportive relationship with a GP:

Yeah, didn’t feel comfortable going to the doctors about it as well. So, so I just kind of thought it was just going to pass. Sucked it up and carried on.

To break through their hesitation, there needed to be some sort of a trigger, including worsening or new symptoms. Making the decision to see a doctor was only the first step in what sometimes became a long process requiring many visits.

Seeking care for indeterminate gut behaviours

One of the key problems was that indeterminate symptoms were hard to articulate even if participants were convinced themselves that something was wrong. In the absence of obviously alarming symptoms that raised concern for the healthcare provider, the participants reported that they had been simply given a reassurance:

I said, ... “there’s something going on inside my tummy, because of these symptoms I’m having.” So, she poked around me and she said, “I can’t feel anything there,” ... No, nothing seemed to be wrong with me.

Alternatively, several participants reported that the doctor made an assumption about what was wrong based on factors such as the participant’s appearance or age:

Everyone was accusing me of an eating disorder, but I actually had coeliac disease. So, that ... was quite traumatic, I suppose. Like I had like lots of people accusing me of vomiting up my food and not eating and stuff, but in reality, I was eating and feeling really sick.

Several participants had their complaints attributed to their previous medical history. In one case, no further investigation was done, yet this participant eventually proved to have a different and more serious condition, which resulted

in emergency surgery. Several participants spoke about how pain seemed to be minimised by doctors or that they could be suspected of drug-seeking.

Responses such as these, which left participants unsatisfied, could then set up a new cycle where they again deferred seeking further help:

... we know that something's not right, and that's not helpful for the medical profession, because if you go in and sit in front of them when you've got like a 5- or 10-minute appointment and you're like, "Something's not right...I've got a funny tummy," which is pretty non-specific. Well, what are they going to do?

Other participants, however, were frustrated, particularly if they had visited their GP many times over several months with the same difficult gut behaviours that were worsening rather than improving:

They must take a serious look at why this patient is here. He must be in pain. Something definitely is not right. People just don't go willy-nilly ... to the doctor because they enjoy going to the doctor. No, they go to the doctor for a reason.

In contrast, to those participants who felt they should have been investigated more thoroughly or sooner, there were some who had been referred to specialists but nothing serious had been found. Although this was a relief, their symptoms were still just as troublesome, leaving them with a perception that their case was considered closed and they should expect no further help unless something about their gut behaviour changed:

I pretty much got told if it gets bad again, come back. "This is what's wrong with you: nothing".

So overall, most of these 22 participants had been, or were still, experiencing lengthy periods where gut behaviour disrupted their lives. Some remained unconvinced with reassurances that there was nothing seriously wrong and continued to work towards a diagnosis. Others accepted that they had disordered gut behaviour that they would need to manage themselves. The next section looks in more detail how this worked out for those who had now been diagnosed and those who had not.

Moving towards a diagnosis – or managing without one...

There was a degree of variability of what happened after people did seek care, reflecting different experiences. In this subgroup of participants, there were a number who had now been diagnosed with diseases such as cancer, coeliac or inflammatory bowel diseases. They gave accounts of struggling with worsening gut behaviours:

Yeah, it got worse and worse to the point where, "No, no, no, there's something damn wrong." I'd think, "Oh I'll get over this," and that sort of attitude, and I'm thinking ... "Oh I'll be alright. Toughen up." But no, I sort of knew there was something wrong.

In hindsight, some believed they should have been more forceful in presenting their concerns and would advise others not to be put off, so 'if you think there's something wrong, make your point and don't leave it'. Nevertheless, going back again and again to the same doctor was awkward, as was seeing a different doctor. Though for some participants, a new doctor who looked at the problem afresh could be a breakthrough:

Like it was 2 years I didn't know what was wrong with me. 10 minutes later, out of that, then yeah, I'm in the hospital, getting checked up.

People in rural areas had fewer options locally, so they might have to leave their own areas to see someone else and to avoid spoiling relations with a family GP they would have to consult in future:

...you don't want to be a pain, I guess. You don't want to keep nagging all the time, depending on what it is. Sometimes I think I would go to [city], I would go privately, find someone else.

The options suggested by this participant are, however, somewhat limited. Enrolling in a GP practice in another centre would be burdensome in terms of time and travel.

Some had accepted that they had a chronically troublesome gut and were focused on managing this. There was a perception among these participants, even those who enjoyed a supportive relationship with their doctor, that they ultimately had to work this out themselves. It could be challenging, particularly in the workplace:

.... there doesn't seem to be any kind of magic pill to make it go away. If you're told, "That's pretty much all we can do for you." ... It still causes a certain level of anxiety, I think, especially when you start a new job, the toilet situation. ... Gosh, I've had jobs in the past where I used to drive home at lunchtime every time just to use my own toilet.

The support that they received from medical professionals appeared to be variable. One participant who had a good relationship with a supportive GP in one place felt let down when they moved to another town and the new doctor did not seem to grasp how severe irritable bowel syndrome (IBS) could be or the impact it had on their life:

... I'd said something about IBS, and [name of doctor] said, "Oh yes, but "It's only a syndrome, or...." I can't

remember what he called it, but what I thought he meant, he was implying that it was possibly all in my head.

This perceived lack of support appeared to be one of the reasons that some participants turned to alternative therapists. None of them claimed their gut problems had been 'cured' by these practitioners, but all participants had been given coping strategies that appeared to have enhanced their confidence in being able to manage their symptoms:

He [the naturopath] was amazingno gluten, no dairy, no alcohol, no coffee, no tea...basically just a very clean diet which was mainly all fresh vegetables and fish and meat, but, you know, everything nice and clean. And then we added in things. ... And it was almost like a lightbulb going off.

The consultations were relatively expensive, and some of what they suggested was potentially quite demanding. Some less-expensive strategies were relatively freely available. These strategies included personal trial-and-error as people learned to avoid certain foods, finding assistance from Facebook posts, interactive chat groups, or general online research for recipes. An interesting aspect of this independent research was that all these participants reported their symptoms improved if they adopted a gluten free diet, even if their doctor said it would not help:

I asked a few different doctors their opinion and they had all said, "Oh no, no, don't. There's no research. It doesn't support it, and no, it won't work." But all the research online from what I was finding online and different ones that had IBS, they were all saying, yes, it does. ... So, I just tried it and it seemed to make a difference...Less bloating, not the same intense pain ... before, I could get it, you know, 2 or 3 times a week. Whereas now I might get it once a fortnight.

The acceptance by these participants that they needed to be self-managing avoided over-medicalisation of their condition and avoided further investigation. But, it also meant that there was no formal surveillance mechanism that would pick up any signs of more serious disease.

The three sections above serve to demonstrate the complexity of the space that exists between having a gut that functions normally and having a disease that can be diagnosed and treated. The participants' experiences did not happen in isolation, but were influenced by the health professionals with whom they interacted. In the following section, we discuss the implications of this complex positioning and provide suggestions that might mitigate some of the issues raised.

Discussion

Much has been written about the power of the medical or clinical 'gaze' and biomedical power, particularly in relation

to the control over the normal and pathological, diagnosis and treatment.^{28,29} The gaze involves the clinician selecting and filtering what is biomedically relevant.³⁰ But as already explained, within biomedicine, not only is it sometimes difficult to discern definite pathology, but the distinction between organic and functional gut disease has been described as an 'inappropriate dichotomy'.^{31,32} By functional disorder, we mean: 'that they do not have a physical cause that can be detected with a microscope, scanners, or blood or genetic tests'.³³ Patel *et al.*³⁴ (2015) found that up to one in six patients without alarming features might have underlying organic gastrointestinal disease, and several studies have suggested that GPs should be alert to patients who present with 'an excess' of gastrointestinal symptoms over a period of years.^{35–37}

It is not only biomedicine that must attempt to distinguish between 'normal' and potentially pathological symptoms. Our participants sat on the edge of the overt clinical gaze knowing what they had been told, but needing to manage none-the-less. Once beyond the clinical interaction, participants had to navigate the dividing line between normal and abnormal themselves, and our participants with troublesome gut behaviours were often resourceful in managing their condition. There appeared to be no formal mechanism, however, for reviewing them other than their being told to come back if their problems worsened. Although responsibilising the patient in this way is unsurprising and even necessary, this led to uncertainties about whether and when to seek help, how to talk about gut issues when seeing a doctor, how persistently to pursue diagnosis, and how to cope with troublesome gut behaviours over a long period. If an initial consultation did not result in an investigation or a diagnosis, there were multiple factors that could deter them from following up their belief that something was just not right.

The situation above leaves lay people/patients in a difficult situation. We are not suggesting that every case must be investigated and reinvestigated. Aside from the obvious problems of the risks associated with investigation, unnecessary investigations can delay positive treatments that might improve quality of life for patients. Such treatments, not always conventionally biomedical, include dietary advice, cognitive therapy, stress management techniques and some medicines.^{38–43} Our participants' experiences, however, suggest that these treatments have not always filtered through into practice, and even if clinicians do refer to these services, they tend, at least in New Zealand, to have long waiting times or require private financial means⁴⁴ that are beyond the financial reach of many.

It might be worth considering formal recall systems, if these do not exist, for those with ongoing gut troubles. Using existing guidelines about referrals to other treatment strategies (dietary, psychological and so on) might be helpful for some. Yet, there is also a constant tension for medical professionals in relation to these symptoms. The majority

of people they see, even if not entirely 'normal', present with symptoms that have a broad range of potential diagnoses.²⁰ There are no validated biomarkers that can measure when common gut behaviours such as heartburn, abdominal rumbling, bloating or cramping change from being a transient annoyance to become concerning.¹⁸ The causes of bloating, for example, are not well understood, treatment is difficult and 'no regimen is consistently successful'.¹⁷ Pain might be attributed to numerous factors.⁴⁵ People with these behaviours are considered to have 'functional' illness; that is, on investigation, there are no detectable biological changes that are present in people who have organic disease.^{46,47}

Recommendations to exclude organic disease before treating people as having functional illness²⁰ can be problematic for general practitioners who act as gatekeepers in a constrained public healthcare system. Largely missing from the literature is any indication of how people with indeterminate gut behaviours could be assisted by their doctors help them. The findings of our study suggest that the standard patient resources on gastrointestinal disease^{21–23} do not fill this gap. Rather than focus on diseases and their symptoms, it might be more useful provide a checklist of gut behaviours with indications of when their severity, frequency, or combinations should raise concern. There is reliable evidence that such campaigns raise awareness of the targeted conditions,⁴⁸ while providing vocabulary to discuss them less awkwardly and reduce people's fear of feeling foolish for 'bothering' the doctor over symptoms that appear mild, intermittent, or had been previously dismissed as unimportant.^{6,49–51}

Such a checklist would need to emphasise and also incorporate a section with a 'tips for talking to your doctor', similar to those provided by the Cancer Society NZ.⁵² As with all tools, a checklist could be misused, and be falsely reassuring to some patients who do not meet pre-determined arbitrary criteria. However, a guidance tool of this nature could provide lay people with information about when to seek care urgently and when to wait to see if their gut settles. The relevant information could be disseminated through a public campaign across multiple media platforms, in different formats, and languages.

Conclusion

The complex position that clinicians and lay people find themselves in, in relation to indeterminate gut behaviours, demands more than a simple critique of the medical gaze to advance the wellbeing of those with ongoing gut problems. These findings made considerable progress in understanding lay people's issues around indeterminate gut behaviours that potentially contribute to delayed diagnosis of gut disease. As well as considering recall systems for those with ongoing gut problems, referring to other management techniques, a widely disseminated pre-consultation information and patient

support tool might be helpful in upskilling the layperson about gut disease. The role of doctors in responding to patients' concerns and the capacity of the wider health system to carry out prompt investigations where they are warranted also need to be addressed. These important areas are beyond the scope of our study and would reward further research.

Supplementary material

Supplementary material is available [online](#).

References

- Gurney J, Stanley J, Jackson C, *et al*. Stage at diagnosis for Māori cancer patients: disparities, similarities and data limitations. *N Z Med J* 2020; 133(1508): 43–64. [published Online First: 17 January 2020]
- Molassiotis A, Wilson B, Brunton L, *et al*. Mapping patients' experiences from initial change in health to cancer diagnosis: a qualitative exploration of patient and system factors mediating this process. *Eur J Cancer Care* 2010; 19(1): 98–109. doi:10.1111/j.1365-2354.2008.01020.x
- Sandler RS, Stewart WF, Liberman JN, *et al*. Abdominal pain, bloating, and diarrhea in the United States. *Dig Dis Sci* 2000; 45(6): 1166–71. doi:10.1023/A:1005554103531
- Sharples KJ, Firth MJ, Hinder VA, *et al*. The New Zealand PIPER Project: colorectal cancer survival according to rurality, ethnicity and socioeconomic deprivation - results from a retrospective cohort study. *N Z Med J* 2018; 131(1476): 24–39. [published Online First: 8 June 2018]
- Dobson CM, Russell AJ, Rubin GP. Patient delay in cancer diagnosis: what do we really mean and can we be more specific? *BMC Health Serv Res* 2014; 14(1): 387. doi:10.1186/1472-6963-14-387
- Hall N, Birt L, Banks J, *et al*. Symptom appraisal and healthcare-seeking for symptoms suggestive of colorectal cancer: a qualitative study. *BMJ Open* 2015; 5(10): e008448. doi:10.1136/bmjopen-2015-008448
- Shahid S, Teng TH, Bessarab D, *et al*. Factors contributing to delayed diagnosis of cancer among Aboriginal people in Australia: a qualitative study. *BMJ Open* 2016; 6(6): e010909. doi:10.1136/bmjopen-2015-010909 [published Online First: 5 June 2016]
- Connell AM, Hilton C, Irvine G, *et al*. Variation of bowel habit in two population samples. *Br Med J* 1965; 2(5470): 1095–9. doi:10.1136/bmj.2.5470.1095
- Mitsuhashi S, Ballou S, Jiang ZG, *et al*. Characterizing normal bowel frequency and consistency in a representative sample of adults in the United States (NHANES). *Am J Gastroenterol* 2018; 113(1): 115–23. doi:10.1038/ajg.2017.213
- Zubaidi AM, Al-Saud NH, Al-Qahtani XA, *et al*. Bowel function and its associated variables in Saudi adults. A population based study. *Saudi Med J* 2012; 33(6): 627–33. [published Online First: 26 June 2012]
- Zutshi M, Hull TL, Bast J, *et al*. Female bowel function: the real story. *Dis Colon Rectum* 2007; 50(3): 351–8. doi:10.1007/s10350-006-0758-0
- Heitmann PT, Vollebregt PF, Knowles CH, *et al*. Understanding the physiology of human defaecation and disorders of continence and evacuation. *Nat Rev Gastroenterol Hepatol* 2021; 18(11): 751–69. doi:10.1038/s41575-021-00487-5
- Jones MP, Shah A, Ben-Jacob R, *et al*. Routine assessment of gastrointestinal symptom using a validated questionnaire in the clinical setting to assess the probability of organic or functional gastrointestinal diseases. *Neurogastroenterol Motil* 2021; 33(8): e14091. doi:https://doi.org/10.1111/nmo.14091
- Koloski NA, Jones M, Hammer J, *et al*. The validity of a new Structured Assessment of Gastrointestinal Symptoms Scale (SAGIS) for evaluating symptoms in the clinical setting. *Dig Dis Sci* 2017; 62(8): 1913–22. doi:10.1007/s10620-017-4599-6

- 15 Revicki DA, Wood M, Wiklund I, et al. Reliability and validity of the gastrointestinal symptom rating scale in patients with gastroesophageal reflux disease. *Qual Life Res* 1997; 7(1): 75–83. doi:10.1023/A:1008841022998
- 16 Brenner D. A noisy tummy: what does it mean? 2020. Available at https://iffgd.org/wp-content/uploads/234_A-Noisy-Tummy-What-Does-it-Mean_UPDATED.pdf [accessed 21 March 2022].
- 17 Lacy BE, Cangemi D, Vazquez-Roque M. Management of chronic abdominal distension and bloating. *Clin Gastroenterol Hepatol* 2021; 19(2): 219–31. doi:10.1016/j.cgh.2020.03.056
- 18 Azpiroz F, Guyonnet D, Donazzolo Y, et al. Digestive symptoms in healthy people and subjects with Irritable Bowel Syndrome: validation of symptom frequency questionnaire. *J Clin Gastroenterol* 2015; 49(7): e64–70. doi: 10.1097/MCG.0000000000000178
- 19 Quigley EMM, Locke GR, Mueller-Lissner S, et al. Prevalence and management of abdominal cramping and pain: a multinational survey. *Aliment Pharm Ther* 2006; 24(2): 411–19. doi:<https://doi.org/10.1111/j.1365-2036.2006.02989.x>
- 20 Sabo CM, Grad S, Dumitrascu DL. Chronic abdominal pain in general practice. *Digestive Dis* 2021; 39(6): 606–14. doi:10.1159/000515433
- 21 Health Navigator. Health A – Z. 2022. Available at <https://www.healthnavigator.org.nz/health-a-z/> [Accessed 21 March 2022].
- 22 MedlinePlus. Health topics: digestive system. 2018. Available at <https://medlineplus.gov/digestivesystem.html> [Accessed 21 March 2022].
- 23 NHS. Health A to Z. 2022. Available at <https://www.nhs.uk/conditions/> [Accessed 21 March 2022].
- 24 Stokes T, Tumilty E, Doolan-Noble F, et al. HealthPathways implementation in a New Zealand health region: a qualitative study using the Consolidated Framework for Implementation Research. *BMJ Open* 2018; 8(12): e025094. doi:10.1136/bmjopen-2018-025094
- 25 Crotty M. The foundations of social research: meaning and perspective in the research process. Thousand Oaks, CA: Sage; 1998.
- 26 Parker C, Scott S, Geddes A. Snowball sampling. Atkinson P, Delamont S, Cernat, A, Sakshaug J & Williams R (eds). SAGE Research Methods Foundations. SAGE Publications Ltd.; 2019. doi:10.4135/9781526421036831710
- 27 Braun V, Clarke V. What can “thematic analysis” offer health and wellbeing researchers? *Int J Qual Stud Heal* 2014; 9(1): 26152. doi:10.3402/qhw.v9.26152
- 28 Armstrong D. Foucault and the Sociology of Health and Illness. in ‘Foucault, Health and Medicine’. London & New York: Routledge; 1997.
- 29 Foucault M. The birth of the clinic. London: Tavistock; 1973.
- 30 Misselbrook D. Foucault. *Br J Gen Pract* 2013; 63(611): 312–12. doi:10.3399/bjgp13X668249
- 31 Drossman DA. Functional versus organic: an inappropriate dichotomy for clinical care. *Am J Gastroenterol* 2006; 101(6): 1172–5. doi:10.1111/j.1572-0241.2006.00592.x
- 32 Grover M, Herfarth H, Drossman DA. The functional–organic dichotomy: postinfectious irritable bowel syndrome and inflammatory bowel disease–irritable bowel syndrome. *Clin Gastroenterol Hepatol* 2009; 7(1): 48–53. doi:10.1016/j.cgh.2008.08.032
- 33 Smith R. “Functional disorders”: one of medicine’s biggest failures. *BMJ* 2023; 221: p221. doi:10.1136/bmj.p221
- 34 Patel P, Bercik P, Morgan DG, Bolino C, Pintos-Sanchez MI, Moayyedi P, Ford AC. Prevalence of organic disease at colonoscopy in patients with symptoms compatible with irritable bowel syndrome: cross-sectional survey. *Scand J Gastroenterol* 2015; 50(7): 816–823. doi:10.3109/00365521.2015.1007079
- 35 Blackwell J, Saxena S, Jayasooriya N, et al. Prevalence and duration of gastrointestinal symptoms before diagnosis of inflammatory bowel disease and predictors of timely specialist review: a population-based study. *J Crohns Colitis* 2020; 15(2): 203–11. doi:10.1093/ecco-jcc/jjaa146
- 36 Maconi G, Orlandini L, Asthana AK, et al. The impact of symptoms, irritable bowel syndrome pattern and diagnostic investigations on the diagnostic delay of Crohn’s disease: a prospective study. *Dig Liver Dis* 2015; 47(8): 646–51. doi:10.1016/j.dld.2015.04.009
- 37 Porter CK, Cash BD, Pimentel M, et al. Risk of inflammatory bowel disease following a diagnosis of irritable bowel syndrome. *BMC Gastroenterol* 2012; 12(1): 55. doi:10.1186/1471-230X-12-55
- 38 Crohns and Colitis Australia. Differentiating between IBS and IBD. Melbourne: Crohns and Colitis Australia; 2013. Available at <https://www.crohnsandcolitis.com.au/site/wp-content/uploads/Differentiating-Between-IBS-and-IBD.pdf> [Accessed 22 February 2021].
- 39 Halpert A, Dalton CB, Palsson O, et al. Irritable bowel syndrome patients’ ideal expectations and recent experiences with healthcare providers: a national survey. *Dig Dis Sci* 2010; 55(2): 375–83. doi:10.1007/s10620-009-0855-8
- 40 Linedale EC, Andrews JM. Diagnosis and management of irritable bowel syndrome: a guide for the generalist. *Med J Aust* 2017; 207(7): 309–15. doi:10.5694/mja17.00457
- 41 Olafsdottir LB, Gudjonsson H, Jonsdottir HH, et al. Irritable bowel syndrome: physicians’ awareness and patients’ experience. *World J Gastroenterol* 2012; 18(28): 3715–20. doi:10.3748/wjg.v18.i28.3715
- 42 Simren M, Palsson OS, Whitehead WE. Update on Rome IV criteria for colorectal disorders: implications for clinical practice. *Curr Gastroenterol Rep* 2017; 19(4): 15. doi:10.1007/s11894-017-0554-0
- 43 Harvey JM, Sibelli A, Chalder T, et al. Desperately seeking a cure: treatment seeking and appraisal in irritable bowel syndrome. *Br J Health Psychol* 2018; 23(3): 561–79. doi:<https://doi.org/10.1111/bjhp.12304>
- 44 McCarthy N. Dietetic care in inflammatory bowel disease in New Zealand. Master of Health Sciences Thesis. University of Otago, Dunedin; 2021.
- 45 Dassieu L, Heino A, Develay É, et al. “They think you’re trying to get the drug”: qualitative investigation of chronic pain patients’ health care experiences during the opioid overdose epidemic in Canada. *Can J Pain* 2021; 5(1): 66–80. doi:10.1080/24740527.2021.1881886
- 46 Bell V, Wilkinson S, Greco M, et al. What is the functional/organic distinction actually doing in psychiatry and neurology? *Wellcome Open Res* 2020; 5: 138. doi:10.12688/wellcomeopenres.16022.1
- 47 Drossman DA. Functional GI disorders: what’s in a name? *Gastroenterology* 2005; 128(7): 1771–2. doi:10.1053/j.gastro.2005.04.020
- 48 Vernon E, Gottesman Z, Warren R. The value of health awareness days, weeks and months: a systematic review. *Soc Sci Med* 2021; 268: 113553. doi:10.1016/j.socscimed.2020.113553
- 49 Jarbøl DE, Rasmussen S, Svendsen RP, et al. Barriers to contacting general practice with alarm symptoms of colorectal cancer: a population-based study. *Fam Pract* 2018; 35(4): 399–405. doi:10.1093/fampra/cmz117
- 50 Morris M, Friedemann Smith C, Boxell E, et al. Quantitative evaluation of an information leaflet to increase prompt help-seeking for gynaecological cancer symptoms. *BMC Public Health* 2016; 16: 374. doi:10.1186/s12889-016-3032-y
- 51 Whitaker KL, Macleod U, Winstanley K, et al. Help seeking for cancer ‘alarm’ symptoms: a qualitative interview study of primary care patients in the UK. *Br J Gen Pract* 2015; 65(631): e96–105. doi:10.3399/bjgp15X683533
- 52 Cancer Society NZ. Tips for talking to your doctor. 2021. Available at <https://www.cancer.org.nz/cancer/types-of-cancer/bowel-cancer/> [Accessed 24 March 2022].

Data availability. These data are confidential and therefore not available.

Conflicts of interest. The authors declare no conflicts of interest.

Declaration of Funding. This research was funded by the Gut Foundation, and the Health Research Council of New Zealand HRC (ref ID 20/1073) Health Delivery Activation Grant.

Acknowledgements. The authors gratefully acknowledge the support of the Gut Foundation and Professor Richard Gearry who made this study possible. We thank all the research participants for their willingness to share their experiences with us. We also thank Associate Professor Konrad Richter (Southland), Dr Omer Hajelssedig (Nelson), and the Cancer Nurses from Canterbury and West Coast District Health Boards for their assistance in recruiting participants. We thank Els Russell for her support in editing this paper.

Author affiliations

^ADepartment of Population Health, University of Otago, Christchurch, 34 Gloucester Street, Christchurch, New Zealand.

^BSchool of Health Sciences, University of Canterbury, New Zealand.