

## ORIGINAL ARTICLE

# Referrals to a tertiary hospital: A window into clinical management issues in functional gastrointestinal disorders

Ecushla C Linedale,\*<sup>1</sup> Muhammad A Shahzad,<sup>†</sup> Andrew R Kellie,<sup>‡</sup> Antonina Mikocka-Walus,\*<sup>§</sup> Peter R Gibson<sup>¶</sup> and Jane M Andrews\*<sup>||</sup>

\*Department of Medicine, The University of Adelaide, <sup>‡</sup>GP Clinic, East Adelaide Health Care, <sup>||</sup>Department of Gastroenterology and Hepatology, Royal Adelaide Hospital, Adelaide, <sup>†</sup>Department of Gastroenterology and Hepatology, The Queen Elizabeth Hospital, Woodville South, South Australia, <sup>§</sup>School of Psychology, Deakin University, Burwood and <sup>¶</sup>Department of Gastroenterology, Monash University, Clayton, Victoria, Australia

### Key words

functional gastrointestinal disorders, irritable bowel syndrome, management, primary care, tertiary care.

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### Correspondence

Dr Ecushla Linedale, Department of Gastroenterology and Hepatology, The Royal Adelaide Hospital, North Terrace, SA 5000, Australia.

Email: ecushla.linedale@adelaide.edu.au

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### Abstract

**Background and Aim:** To investigate the quality of and reasons for referrals of patients with likely functional gastrointestinal disorders (FGID) and explore patients' experience of clinical management.

**Methods:** A cross sectional, mixed-methods study was undertaken. Referrals (July 2013–2015) to one gastroenterology outpatient department triaged as “likely FGID”, the referred patients and their referring primary healthcare providers were examined.

**Results:** A total of 69% of patients reported not yet receiving an initial diagnosis, 52% reported persistent/distressing symptoms or reduced quality of life, 24% feared missed or worsening pathology, and 35% were seeking repeat specialist consultation. Most patients were dissatisfied (40%) or only partially satisfied (36%) with current management. Dissatisfaction was significantly related to the lack of provision of a diagnosis and effective treatment options ( $P < 0.001$ ). Referral quality was poor and with the reason for referral clearly communicated in only 25%. Common referral reasons included repeat presentations ( $n = 32$ ), diagnostic uncertainty ( $n = 19$ ), to ensure nothing is missed ( $n = 19$ ), patient request ( $n = 17$ ), no response to treatment ( $n = 16$ ), and to allay patient fears ( $n = 14$ ). A total of 28/60 primary healthcare providers were confident that their patient had a FGID, yet sought confirmation ( $n = 16$ ), second opinion ( $n = 8$ ), or advice ( $n = 4$ ).

**Conclusion:** Current management of FGID in usual care is suboptimal, as evidenced by the tertiary referral load, patient dissatisfaction, and the lack of provision of diagnoses and effective treatment options. Some clinicians lack confidence in effectively identifying and managing these conditions. Resources and supports to equip and assist clinicians to identify and manage FGID successfully may enhance patient care.

## Introduction

Globally, functional gastrointestinal disorders (FGIDs) pose a significant and growing public health problem.<sup>1</sup> It is estimated that 40% of the population will be affected by one or more FGIDs within their lifetime, with irritable bowel syndrome (IBS) and functional dyspepsia the most common.<sup>1,2</sup> These chronic, recurrent conditions impair quality of life and present a significant economic cost due to ongoing patient distress, unnecessary investigations, repeated healthcare visits, and workplace impairment.<sup>1,3</sup> In 2000, an estimated \$US 41 billion was spent on IBS alone in the UK, Japan, Australia, Sweden, Germany, France, and Canada.<sup>4</sup>

Historically, FGIDs were regarded as diagnoses of exclusion, leading to unnecessary investigations,<sup>5</sup> but can now be positively diagnosed based on symptoms, red flag exclusion and simple, and relevant exclusionary tests.<sup>6–10</sup> The UK's National Institute of Clinical Excellence recommend FGID be diagnosed and managed within

primary care and referred to gastroenterology after 1 year if disturbing symptoms persist.<sup>11</sup> However, most clinicians (72%) still regard IBS as a diagnosis of exclusion.<sup>12</sup> Few primary healthcare providers (PHCPs) are aware of (2–36%) or use (0–21%) FGID diagnostic criteria and 4–40% of cases are referred to specialist care<sup>13</sup> (11% in Australia).<sup>14</sup> Variability in primary care management is reflected in individual PHCP referral rates ranging 1–80%,<sup>15</sup> with FGID referrals accounting for 30–50% of gastroenterology consultations.<sup>16,17</sup> In the Australian health system, gastroenterologist consultation cannot be accessed without referral from PHCPs. Furthermore, referrals to public gastroenterology outpatient clinics are triaged according to clinical urgency, and those with clinically suspected functional gastrointestinal symptoms are deferred to very long waiting lists, with many patients never being seen.<sup>18</sup>

Limited health resources and large open-ended referral loads have frustrated patients, PHCPs and gastroenterologists

alike. Understanding what drives referrals is essential to addressing this growing public health problem. This study aimed to describe the quality and drivers of referrals for patients with likely FGID, and explore patient experience of clinical management in the context of Australian health care.

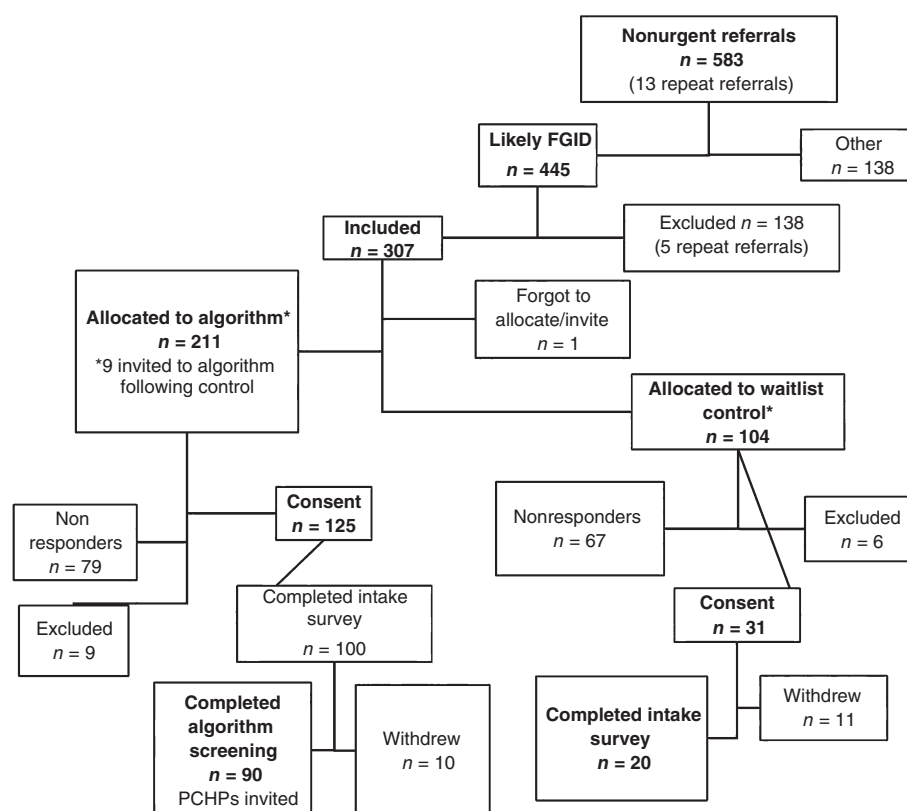
## Methods

This cross-sectional, mixed-methods study is nested within a controlled pilot trial of an algorithm-based approach to the diagnosis and management of FGID.<sup>19</sup> All patients (18–75 years) referred to one gastroenterology outpatient department (June 2013–July 2015) in a tertiary referral center (metropolitan city of 1.3 million people), triaged as “likely FGID” with chronic or recurrent epigastric/abdominal pain with or without altered bowel habit (diarrhea, constipation or both), bloating, nausea and vomiting, and the absence of red flags, were invited ( $n = 382$ ) (Fig. 1). Patients were excluded where the referral indicated predominant reflux symptoms, evidence of current *Helicobacter pylori* infection, positive fecal occult blood test or recent symptom onset (<6 months), pregnancy, cognitive impairment or poor English communication skills. Participants completed a demographic survey ( $n = 110$ ) and those randomized to the algorithm group (2:1 ratio, sequentially) completed an additional structured medical history questionnaire ( $n = 90$ ). Referring PHCPs (of algorithm group) were invited to complete a patient-specific, anonymous questionnaire comprising open-ended and multiple-selection questions regarding reasons for referral and confidence in

diagnosing FGID. Patient symptom severity was measured by the Gastrointestinal Symptom Rating Scale<sup>20</sup> across five dimensions on a 7-point Likert scale with seven being the most negative.

**Data analysis.** Referral quality was assessed with content analysis, following the steps outlined by Neuendorf.<sup>21</sup> Coding categories assessed corresponded to routine referral triage criteria and were prospectively defined by a Senior Gastroenterologist (JMA). These included legibility, clear reason for referral, inclusion of relevant patient demographics (age, gender), medical information (symptoms, symptom duration, clinical alarms, provisional diagnosis), comorbidities (psychological and medical), psychosocial history and its relevance to symptoms. A set of 10 referrals were analyzed by two independent coders (EL, MS), coding compared and final categories/rules decided by consensus between all investigators. In total, 90 referrals were coded and frequencies recorded. Referral codes were verified back to the raw data (EL) to ensure coding consistency. Referral data were compared to patient questionnaire responses, and discrepancies corrected by consensus (MS, EL).

Open-form responses from both patient and PHCP questionnaires were also subject to content analysis (EL, JMA). Where appropriate, codes were combined to explore over-arching themes in the responses. Data were analyzed using SPSS 24 (IBM Corp., Armonk, NY, USA). Mean and SD or median and interquartile range (IQR) were reported for ordinal data. Pearson's Chi-square test of association was conducted where appropriate, with significance  $\leq 0.05$ .



**Figure 1** Flowchart of participant selection. FGID, functional gastrointestinal disorders; PCHP, primary healthcare provider.

**Ethics approval.** This protocol received Human Research Ethics Approval. All participants received an information sheet, were given the opportunity to ask further questions by telephone prior to intake, and gave informed consent. **Trial registration:** ANZCTR, ACTRN12614000602628.

## Results

### Patient description

**Demographics.** Patients who completed the intake survey ( $n = 110$ , Fig. 1) were 64% female, 54% married/de facto, with mean age 42 years (SD 15). The median time on waitlist was 113 days (IQR 69–217). Most were in paid employment (24% part-time, 37% full-time) and had completed high school or further education (80%) (Table 1). Nonresponders were comparable to responders in age, gender, and time on waitlist.

Symptom duration was greater than 2 years in 69% (24% >10 years) of patients. A gastroenterologist had been previously consulted in 35% of patients (53% of these, more than once) and 25% of patients had presented to hospital (79% of these, more than once) for their gastrointestinal symptoms. A third of the repeat-consulters (14/38) had seen the gastroenterologist within the past 2 years. Medical and psychological comorbidities were common (56% and 40%, respectively). First-time and repeat specialist consulters were comparable in age, gender, relationship and employment status, and presence of medical and psychological comorbidities. However, repeat consulters had a significantly longer symptom duration (Mean = 20.7 years, SD 29.6) than first-time consulters (Mean = 5.6 years, SD 12.8,  $t(105) = 3.699$ ,

$P < 0.001$ ). Six patients in the algorithm group were diagnosed with organic disease following the algorithm-based screening tests (two inflammatory bowel disease, one neoplasm, one pancreatic insufficiency, one reflux esophagitis, one dietary iron deficiency).

**Health characteristics.** The majority (78%) of patients were using  $\geq 1$  treatment with little or no symptomatic improvement in 69% of these. In the previous 4 weeks, 60% had presented to their PHCP (61% of these gastrointestinal-related) and 3% to the Emergency Department. A total of 67% of patients had spent from \$5 to \$1000 (median \$45, IQR \$23–\$100) on treatment in the previous 4 weeks. One spent over \$1000 flying interstate to seek medical help from a gastroenterologist perceived to have greater expertise and two commented on a lack of funds for treatment (“*I don’t have much money to spend*” Patient 73, “*\$12 for scripts. No other because of lack of funds*” Patient 104). Allied health professionals were consulted by 14% of patients within the previous 4 weeks, with an average cost of \$90 (IQR \$63–\$263). Three patients had not spent money on allied health because they had “*given up*” (Patients 55, 87) or seen “*little or no effect*” (Patient 83), and a few indicated that they “*cannot afford*” allied health (Patients 75, 90).

Overall, patient satisfaction with symptoms was low (median = 3, IQR 1–5) varying along a 10-point Likert scale (lower values indicating lesser satisfaction). Persistent/distressing symptoms were reported by 38% of patients, and an additional 8% experienced reduced quality of life (Fig. 2). At intake, 19 (17%) reported few or no symptoms and attributed this to variability in their symptom presentation. Symptom severity (Gastrointestinal

**Table 1** Personal and clinical demographics of patients referred with suspected FGID ( $n = 110$ )

Personal Demographics		All patients ( $n = 110$ ) $n$ (%)	Prior Gastroenterologist Consultation	
			No ( $n = 72$ ) $n$ (%)	Yes ( $n = 38$ ) $n$ (%)
Gender	Female	71 (64)	46 (64)	24 (63)
Primary language	English	98 (89)	63 (88)	35 (92)
Relationship status	Married/De facto	60 (54)	40 (56)	20 (73)
Employment status	Full-time (>35 h/week)	41 (37)	28 (39)	13 (34)
	Part-time (<35 h/week)	27 (24)	16 (22)	11 (29)
Education level	Year 11 or below	23 (21)	15 (21)	8 (21)
	Year 12	22 (20)	15 (21)	6 (16)
	Higher education	66 (60)	42 (58)	24 (63)
<i>Clinical Demographics</i>				
Symptom satisfaction score reason	Persistent/distressing symptoms	42 (38)	28 (39)	14 (37)
	Symptoms currently ok	22 (21)	17 (24)	5 (13)
	Quality of life severely impacted	9 (8)	6 (8)	3 (8)
	No diagnosis or management	5 (5)	4 (6)	1 (3)
	Ok when medicated only	4 (4)	2 (3)	2 (5)
	Fear it could be something serious	2 (2)	1 (1)	1 (3)
	No reason given	26 (24)	14 (19.4)	12 (11)
Diagnosed by referring PHCP		34 (31)	18 (25)	16 (42)
Satisfaction with management	Well satisfied	12 (11)	6 (8)	6 (16)
	Satisfied	22 (20)	18 (25)	4 (11)
	Partially satisfied	36 (33)	23 (32)	13 (34)
	Unsatisfied	40 (36)	25 (35)	15 (40)
Medical comorbidities reported		61 (56)	41 (57)	20 (53)
Psychological comorbidities reported		44 (40)	29 (40)	15 (40)

Symptom Rating Scale) cohort results were: diarrhea syndrome median = 2 (IQR 1–4), indigestion syndrome median = 3 (IQR 2–4) constipation syndrome median = 2 (IQR 2–4), abdominal pain syndrome median = 3 (IQR 2–4), reflux syndrome median = 2 (IQR 1–3). First-time and repeat gastroenterologist consulters were comparable in symptom severity, symptom satisfaction, symptom response to current treatment, as well as healthcare utilization and cost of treatment over the past 4 weeks.

**Patient reported description of management.** Most patients reported not having been given a diagnosis by their PHCP (76/110, 69%), whilst 18% reported provisional diagnoses of IBS (20/110; 8 being uncertain) and 4% (5/110) reflux-related disorders. Similarly, nearly half who previously consulted a

gastroenterologist reported not receiving a diagnosis (18/38) (Table 2). The most common specialist diagnoses acknowledged included IBS ( $n = 9$ ; 2 being uncertain) and reflux/gastritis ( $n = 4$ ) with three patients unable to recall the diagnosis. Patients expressed concern about painful/distressing symptoms (37%) and fear of missed serious pathology or symptom progression to something more serious (24%) (Table S1, Supporting information).

**Satisfaction with management.** Patient satisfaction with management at intake was poor: 40% dissatisfied and 36% only partially satisfied, with no difference between first-time and repeat consulters (Fig. 2). Only 12 patients reported being well satisfied. The lack of provision of a diagnosis, lack of effective treatment options, frustration with the “system”, and the belief that further investigations were needed emerged as themes in patients’ responses regarding management (Table 3). Dissatisfaction was significantly related to the “lack of provision of a diagnosis/treatment options” ( $\chi^2(33) = 76.985$ ,  $P < 0.001$ ), with 33% of partial/fully dissatisfied patients reporting lack of diagnosis. In addition, 16% of dissatisfied patients were satisfied with their PHCP but awaited a specialist appointment, 12% reported ineffective management options and 12% dissatisfaction with PHCP.

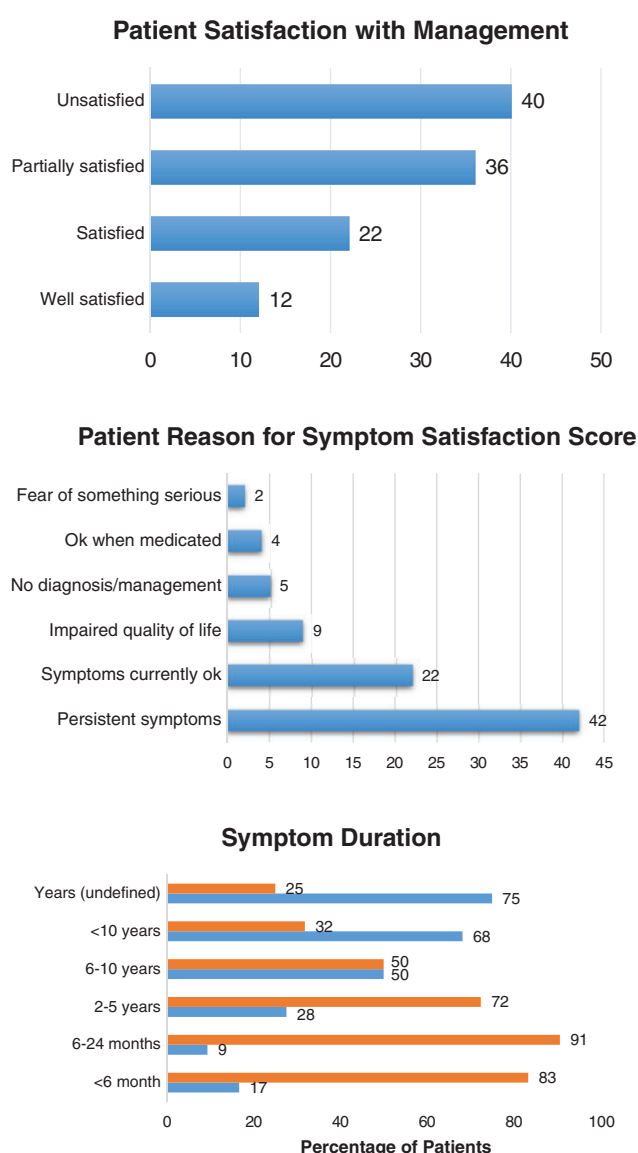
### Description of referrals

**Profile of referring PHCPs.** Referral quality was assessed for patients allocated to the algorithm group who completed the intake survey ( $n = 100$ , Fig. 1); 89 were unique referrals from 78 PHCPs in 60 practices, 11 were referrals from other units within the hospital. Of the 90 PHCP requests (to 78 PHCPs) to complete a patient-specific survey, 61 (68%) responded (36 males); 42/61 were at least 40 years of age and 50/61 has 6 or more years’ experience as a primary healthcare physician ( $n = 39 > 10$  years, 23  $> 20$  years).

**Referral quality.** Overall, referral quality was poor; 6% were poorly legible, and many lacked basic information such as patient age (49%), gender (27%), symptom duration (50%), smoking status (96%), alcohol history (94%), and medical (33%), and psychological (84%) comorbidities. Issues related to mental health and alcohol appeared to be automatically generated and were not integrated into referral narrative.

Clinical alarms were not considered in 71% of referrals. Alarms were consistently underreported when compared to patient responses from the structured health questionnaire (Fig. 3). Provisional diagnoses and clear reasoning for the referral were not provided in 68% and 75% of referrals, respectively. Endoscopies were requested in 33% of referrals and 40% of these failed to provide a reason for the request.

**Reasons for referral.** Despite comment from one PHCP that “there is usually a very good reason to refer to a consultant; unavailability of an investigation, uncertainty of diagnosis, patient anxiety etc.”, reasons were clearly communicated in only 25% of referrals (Fig. 4). The most common reason stated in the referral was to request investigations or patient request. When directly asked for the reason for the referral, a third of PHCPs did not provide a rationale for the referral; 16 simply relisted the symptoms and 4 declined to answer. Where reasons



**Figure 2** Clinical demographics of patients referred with suspected FGID. ■, No prior GE consult; ■, prior GE consult.

**Table 2** Patient reported existing or provisional diagnoses

Reported diagnosis	Total <i>n</i> = 110	Patients who had not seen a specialist <i>n</i> = 72	Patients with prior gastroenterologist consult <i>n</i> = 38
No diagnosis given	69 (63)	54 (75)	18 (47)
IBS	11 (10)	6 (8)	7 (18)
Possible IBS	8 (7)	5 (7)	2 (5)
IBS plus other	3 (3)		
Reflux/heartburn/dyspepsia/gastritis	3 (3)	1 (1)	4 (11)
Possible peptic/gastric ulcer	2 (2)	2 (3)	
Gastric ulcer	1 (1)	1 (1)	
Diagnosis not reported by patient	2 (2)		2 (5)
Gallstones	1 (1)	1 (1)	
Possible gallstones	1 (1)		
Fatty liver	1 (1)		1 (3)
"Collapsed colon" and fatty liver	1 (1)	1 (1)	
Diverticulosis	1 (1)		
HP Infection	2 (2)		1 (3)
"A floppy valve-esophagus"	1 (1)		1 (3)
"Hemorrhoids, narrow colon near anus"	1 (1)		1 (3)
Hiatus hernia	1 (1)		1 (3)
Lactose intolerance/? underlying issue	1 (1)	1 (1)	

FGID, functional gastrointestinal disorders; PHCP, primary healthcare provider.

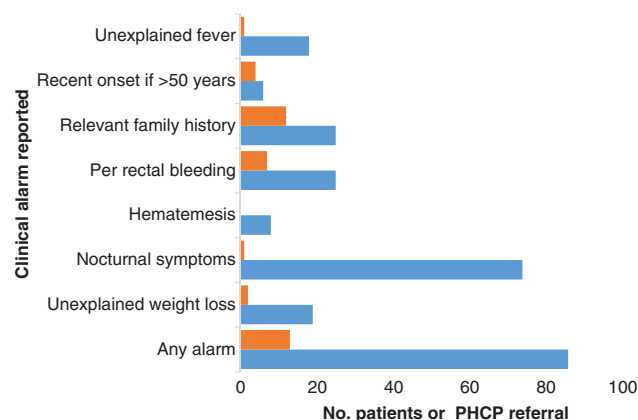
**Table 3** Themes of patient response to satisfaction with management

Theme	Example
No diagnosis and/or management	<ul style="list-style-type: none"> <li>"... has offered no assistance, has told me I need to learn to live with it"</li> <li>"Have no diagnosis, nor any idea how to treat it"</li> <li>"I...was only given pain relief which seems to put a Band-Aid on the problem but has not solved why, or what is causing the problem"</li> <li>"I've seen different PHCP's and at this stage, all they have been able to offer me are various tests. This has been going on for a few years"</li> </ul>
Frustration	<ul style="list-style-type: none"> <li>"My PHCP is trying his best but now I can't afford private health insurance I am on long public waitlists when I am extremely ill"</li> <li>"Long waiting lists, difficulty getting started / getting healthcare going"</li> <li>"No results, constant hand balling. Ultimately no relief and now on a 12-month waiting list for the next step"</li> <li>"She tries her best; it is not her fault that the system is completely broken"</li> <li>"The public system sucks"</li> </ul>
Belief that further investigations are needed	<ul style="list-style-type: none"> <li>"My current doctor has done all he can but because I haven't had an endoscopy or colonoscopy he can't really do much"</li> <li>"I am still not fully diagnosed, therefore I am concerned to know what my health problem is and how to manage it"</li> <li>"PHCP has investigated with no success then referred to specialist, have not seen a specialist yet"</li> <li>"I doubt my PHCP knew it would be this long and still no colonoscopy. I hope once I have this we can plan treatment"</li> <li>"To cover all bases, she sent me to have an ultrasound, which came back clear. Next step was obviously to have the colonoscopy but the way it looks I won't be seen for a long time. I wish she had another idea of what it could be and how to investigate it but it seems not...pity"</li> </ul>

PHCP, primary healthcare provider.

were stated, common reasons included: persistent symptoms, request for endoscopic procedure, inability to reach a diagnosis and confirmation of diagnosis. Other reasons selected from a structured list included to ensure nothing is missed, non-response to treatment, allay patient fears and inability to meet patients demands.

Approximately half the PHCPs (28/60) were confident that their patient had a FGID in response to the forced multiple choice question "Based on your current investigations, are you confident that this patient has a functional gastrointestinal disorder?". Of these, 16 sought confirmation of the diagnosis, 4 treatment advice and 8 a second opinion at patient request. A third



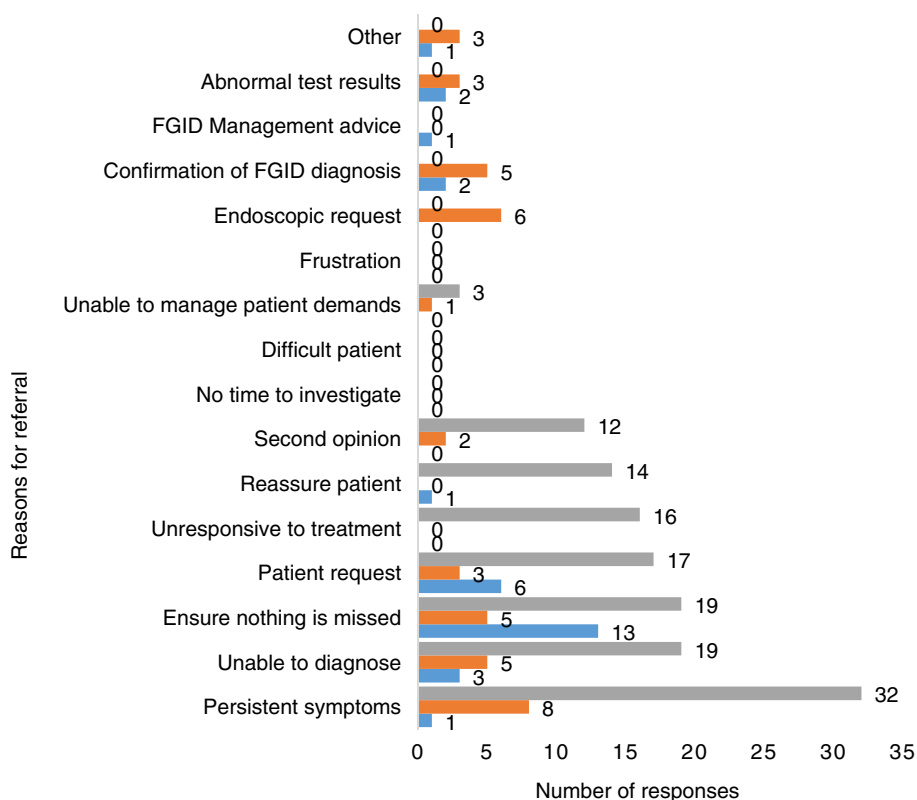
**Figure 3** Comparison of the frequency of patient reported clinical alarms *versus* PHCP referrals. ■, PHCP; ■, patients. PHCP, primary healthcare provider

(27/60) indicated that they were “*unsure*” ( $n = 20$ ) or “*not confident*” ( $n = 7$ ) and would like advice. One PHCP commented “*I am very happy to manage functional GIT disorders and would not refer these to a GI unit unless I felt a SOL [space-occupying lesion] needed exclusion*”. Five PHCPs were confident of an alternative organic diagnosis (although three could not suggest what this was).

## Discussion

The referrals, and PHCP and patient surveys provide a novel, multi-faceted window into the real-world management of FGIDs in Australia. The use of both qualitative and quantitative analyses yields rich information on patient and practitioner perspectives to help better explain how and why the model of care for this highly prevalent group of disorders needs changing. The delivery of better quality care is important to the patient and community given the high prevalence, morbidity, and cost of these disorders. This study identifies four important issues which represent opportunities to improve the management of FGIDs: (i) patient dissatisfaction with management despite recent PHCP consultation or previous gastroenterologist consultation; (ii) the lack of provision (and/or acceptance (22)) of a clear diagnosis to patients (in both primary and tertiary care); (iii) low real-world confidence of some clinicians in diagnosing and communicating a FGID diagnosis; and (iv) poor referral quality reducing triage safety.

Whilst patient-reported symptoms might be considered subjective and exaggerated, (particularly in FGID with high rates of anxiety and/or depression), patient satisfaction with care is a valid and important indicator of effective management. A significant proportion of patients were dissatisfied with both primary and tertiary care management. Dissatisfaction was related to the lack of diagnosis and treatment options and is a potential driver of repeat consultation. Our findings are consistent with previous studies describing the dissatisfaction of patients with FGIDs with the



**Figure 4** Reasons for referrals as stated in referral and primary healthcare provider survey responses. ■, Structured question (tick all that apply) ( $n = 61$ ); ■, open response question ( $n = 61$ ); ■, stated in referral ( $n = 100$ ).

healthcare system.<sup>22,23</sup> Those studies found that patients felt abandoned by healthcare and received inadequate information about their disorder and how to manage their symptoms.<sup>22,23</sup> The expectations and experience of patients with FGID with the clinical consultation often differ from those of the clinician.<sup>24,25</sup> Patients place a high value on being able to understand their condition following the consult, as well as the care and concern of their doctor.<sup>24,26</sup>

The provision of a clear, timely, accurate diagnosis is recommended to move patients from a prolonged diagnostic search to an effective management pathway. The reported lack of diagnosis may be due to a number of factors, such as poor patient recall, patient nonacceptance of a functional diagnosis,<sup>25</sup> or poor communication of diagnosis by the clinician.<sup>27</sup> Although this study cannot distinguish between lack of recall and lack of actual diagnosis, poor recall is less likely as patients were willing to report “unsure” or “possible” IBS diagnoses, which aligns with previous findings that patients with medically unexplained symptoms (such as FGIDs) often report many more diagnoses than can be confirmed.<sup>28</sup> Patient reluctance to accept or acknowledge a functional diagnosis has been previously documented.<sup>25,29</sup> However, the lack of diagnostic documentation (neither provisional nor confirmed diagnoses) in the referrals supports the lack of provision of a diagnosis rather than patient nonacceptance of a functional diagnosis in this study.

Recent studies have shown that most clinicians continue to regard IBS as a diagnosis of exclusion.<sup>12,30</sup> Only 52% of gastroenterologists and 34% of PHCPs were confident diagnosing IBS based on symptoms, history and physical exam, with less than half of these confident to inform the patient without further investigations.<sup>12</sup> This is also supported by the reluctance of PHCPs to add IBS read-codes to patient records until more serious pathology was excluded.<sup>31</sup> Although FGIDs are largely managed in primary care, this study together with the specialist FGID referral load suggests that the real-world confidence of clinicians in diagnosing FGIDs and communicating in some instances is low.

A significant proportion of PHCPs, referred for confirmation of a FGID diagnosis (not stated in referral), at the request of the patients, or for further investigations. This is in keeping with previous findings, that many clinicians may consider a functional diagnosis but are reluctant to communicate this to the patient<sup>32</sup> or to document it<sup>33</sup> without further investigation. The PHCP sample was slightly younger and less experienced than the national average: 31% were under 40 years compared with 24% under 44 years nationally; 43% had been in practice for more 20 years compared to 64%.<sup>34</sup> As PHCP surveys were unidentified, we were unable to explore whether lack of diagnostic confidence was related to age or experience. However, the paucity of provisional diagnoses of IBS flagged in the referrals, suggests this problem crosses experience and age. PHCPs' perception of the necessity for further investigations in the absence of alarm features was also reflected in the patients' belief that they could receive no diagnosis or treatment options until endoscopic procedures were performed. The tertiary referrals analyzed may reflect a cohort of clinicians who struggle to manage FGID, a particularly difficult patient group, or a complex symptom set.<sup>15,16</sup> Although low confidence in diagnosing and/or managing FGIDs was found to be the main reason for these referrals, we cannot however determine the contributing factors which led to the inability to diagnose or manage these specific patients in primary care.

Paradoxically, although long-term nonprogressive symptoms are highly likely to be functional, chronic symptoms appear to also be driving diagnostic uncertainty and desire for specialist input to exclude other diagnoses and reassure patients. Although specialist input is not unreasonable, current public health resources cannot fund the demand. Consistent with this reality, current guidelines recommend an initial diagnosis based on symptomatology, followed up with simple investigations, prior to receiving a clinical diagnosis of FGID,<sup>11,35</sup> and National Institute of Clinical Excellence guidelines recommend this occurs within primary care.<sup>36</sup> The incidence of organic disease detected upon screening may reflect suboptimal screening within primary care, or poor referral quality. In each of these cases, if the referral had included relevant positive and negative alarm features (as per usual guidelines for the clinical diagnosis of FGIDs) these referrals would have initially received a high triage category and patients seen promptly. Primary care clinical pathways for the diagnosis and management of FGIDs, may help reduce referral burden, assist in early, effective diagnosis and management and ensure appropriate identification of clinical alarms requiring urgent gastroenterology review.

FGID management can be challenging. Persistent symptoms that fluctuate in severity or even change are not uncommon, with patients rarely becoming totally symptom-free.<sup>37,38</sup> There is, however, consensus on both the diagnostic and management approach that should be taken. Further studies within primary care are needed to ascertain PHCP awareness of how FGID should be diagnosed and managed according to current best practice. Efforts to develop locally relevant consensus and shared belief between primary and tertiary care on best practice, and clinical pathways which promote quality patient care are needed. An assessment of the quality and availability of PHCP resources (e.g. online pathways, educational sessions), opportunities to partner with specialists to develop and deliver best practice approaches (which include referrals), and of other barriers such as funding structures and access to FGID specialized allied health professionals will also inform where gains can be made. With this and the data from the current study, the development of FGID clinical pathways may streamline and optimize patient care across primary and tertiary sectors.

The generalizability of these findings may be limited, as it was conducted in one tertiary hospital. However, this appears unlikely as a recent systematic review of 29 studies (Europe, North America, Middle East; South East Asia) found 4–40% of patients suspected of having FGID were referred for specialist consultation,<sup>13</sup> indicating that our referral load and management problems are not unique. A strength of our study is the use of a mixed methods approach to triangulate data from actual referrals, referring PHCPs and the patients themselves, to gain a more comprehensive understanding of FGID management.

Current FGID management is suboptimal, as evidenced by the tertiary referral load, patient dissatisfaction, the lack of provision of diagnoses and effective treatment options, and long waiting lists for specialist review. Some clinicians lack confidence in effectively identifying and managing these conditions, which may stem from a lack of awareness of current best practice and how to access evidence-based management options. Further research into FGID management is needed to develop resources such as clinical guidelines, pathways and structured online referrals which may improve patient care.



## References

- Talley NJ. Functional gastrointestinal disorders as a public health problem. *Neurogastroenterol. Motil.* 2008; **20**(Suppl. 1): 121–9.
- Chang JY, Locke GR, McNally MA *et al.* Impact of functional gastrointestinal disorders on survival in the community. *Am. J. Gastroenterol.* 2010; **105**: 822–32.
- Fortea J, Prior M. Irritable bowel syndrome with constipation: a European-focused systematic literature review of disease burden. *J. Med. Econ.* 2013; **16**: 329–41.
- Fullerton S. Functional digestive disorders (FDD) in the year 2000—economic impact. *Eur. J. Surg.* 1998; **164**(S12): 62–4.
- Spiegel BM. Do physicians follow evidence-based guidelines in the diagnostic work-up of IBS? *Nat. Clin. Pract. Gastroenterol. Hepatol.* 2007; **4**: 296–7.
- Cash BD, Chey WD. Irritable bowel syndrome - an evidence-based approach to diagnosis. *Aliment. Pharmacol. Ther.* 2004; **19**: 1235–45.
- Begtrup LM, Engsbro AL, Kjeldsen J *et al.* A positive diagnostic strategy is noninferior to a strategy of exclusion for patients with irritable bowel syndrome. *Clin. Gastroenterol. Hepatol.* 2013; **11**: 956–62.e1.
- Hulisz D. The burden of illness of irritable bowel syndrome: current challenges and hope for the future. *J. Manag. Care Pharm.* 2004; **10**: 299–309.
- Drossman DA, Dumitrascu DL, Rome III. New standard for functional gastrointestinal disorders. *J. Gastrointest. Liver Dis.* 2006; **15**: 237–41.
- Drossman DA. Functional gastrointestinal disorders: history, pathophysiology, clinical features, and Rome IV. *Gastroenterology.* 2016; **150**: 1262–79.e2.
- Dalrymple J, Bullock I. Diagnosis and management of irritable bowel syndrome in adults in primary care: summary of NICE guidance. *BMJ.* 2008; **336**: 556–8.
- Spiegel BM, Farid M, Esrailian E, Talley J, Chang L. Is irritable bowel syndrome a diagnosis of exclusion?: A survey of primary care providers, gastroenterologists, and IBS experts. *Am. J. Gastroenterol.* 2010; **105**: 848–58.
- Hungin APS, Molloy-Bland M, Claes R *et al.* Systematic review: the perceptions, diagnosis and management of irritable bowel syndrome in primary care – A Rome Foundation Working Team Report. *Aliment. Pharmacol. Ther.* 2014; **40**: 1133–45.
- Charles J, Harrison C. Irritable bowel syndrome in Australian general practice. *Aust. Fam. Physician.* 2006; **35**: 840–1.
- Thompson WG, Heaton KW, Smyth GT, Smyth C. Irritable bowel syndrome: the view from general practice. *Eur. J. Gastroenterol. Hepatol.* 1997; **9**: 689.
- Shivaji UN, Ford AC. Prevalence of functional gastrointestinal disorders among consecutive new patient referrals to a gastroenterology clinic. *Frontline Gastroenterol.* 2014; **5**: 266.
- Mitchell CM, Drossman DA. Survey of the AGA membership relating to patients with functional gastrointestinal disorders. *Gastroenterology.* 1987; **92**(5 Pt 1): 1282–4.
- Novak KL, Kathol B, Swain MG *et al.* Sa1074 Nurse-led, interactive group sessions for dyspepsia and GERD referrals: a prospective controlled study of the "Nurse Navigator" clinic. *Gastroenterology.* 2014; **146**: S192–S193.
- Linedale EC, Mikocka-Walus A, Vincent AD, Gibson PR, Andrews JM. Performance of an algorithm-based approach to the diagnosis and management of functional gastrointestinal disorders: A pilot trial. *Neurogastroenterol. Motil.* (in press); <https://doi.org/10.1111/nmo.13243>
- Svedlund J, Sjodin I, Dotevall G. GSRS—a clinical rating scale for gastrointestinal symptoms in patients with irritable bowel syndrome and peptic ulcer disease. *Dig. Dis. Sci.* 1988; **33**: 129–34.
- Neuendorf KA. *The Content Analysis Guidebook*. Thousand Oaks, CA, USA: SAGE Publications, 2002.
- Hakanson C, Sahlberg-Blom E, Ternstedt BM. Being in the patient position: experiences of health care among people with irritable bowel syndrome. *Qual. Health Res.* 2010; **20**: 1116–27.
- Bertram S, Kurland M, Lydick E, Locke GR 3rd, Yawn BP. The patient's perspective of irritable bowel syndrome. *J. Fam. Pract.* 2001; **50**: 521–5.
- Halpert A, Dalton CB, Palsen O *et al.* Irritable bowel syndrome patients' ideal expectations and recent experiences with healthcare providers: a national survey. *Dig. Dis. Sci.* 2010; **55**: 375–83.
- Collins J, Farrall E, Turnbull DA, Hetzel DJ, Holtmann G, Andrews JM. Do we know what patients want? The doctor-patient communication gap in functional gastrointestinal disorders. *Clin. Gastroenterol. Hepatol.* 2009; **7**: 1252–4, e1–2.
- Halpert A. Irritable bowel syndrome: what do patients really want? *Curr. Gastroenterol. Rep.* 2011; **13**: 331–5.
- Linedale EC, Chur-Hansen A, Mikocka-Walus A, Gibson PR, Andrews JM. Uncertain diagnostic language affects further studies, endoscopies, and repeat consultations for patients with functional gastrointestinal disorders. *Clin. Gastroenterol. Hepatol.* 2016; **14**: 1735–41.
- Schrag A, Brown RJ, Trimble MR. Reliability of self-reported diagnoses in patients with neurologically unexplained symptoms. *J. Neurol. Neurosurg. Psychiatry.* 2004; **75**: 608.
- Lau MSY, Ford AC. Do lay people accept a positive diagnosis of irritable bowel syndrome? *Gastroenterology.* 2015; **149**: 252–3.
- Andresen V, Whorwell P, Fortea J, Auziere S. An exploration of the barriers to the confident diagnosis of irritable bowel syndrome: a survey among general practitioners, gastroenterologists and experts in five European countries. *United European Gastroenterol. J.* 2015; **3**: 39–52.
- Harkness EF, Harrington V, Hinder S *et al.* GP perspectives of irritable bowel syndrome—an accepted illness, but management deviates from guidelines: a qualitative study. *BMC Fam. Pract.* 2013; **14**: 92.
- Mearin F, Lacy BE. Diagnostic criteria in IBS: useful or not? *Neurogastroenterol. Motil.* 2012; **24**: 791–801.
- Harkness EF, Grant L, O'Brien SJ, Chew-Graham CA, Thompson DG. Using read codes to identify patients with irritable bowel syndrome in general practice: a database study. *BMC Fam. Pract.* 2013; **14**: 183.
- Britt H, Miller GC, Henderson J *et al.* *General Practice Activity in Australia 2013–14*. Sydney, Australia: Sydney University Press, 2014.
- Begtrup LM, Engsbro AL, Kjeldsen J *et al.* A positive diagnostic strategy is noninferior to a strategy of exclusion for patients with irritable bowel syndrome; 2013, **11**: 956–62, e1.
- NICE. *Irritable Bowel Syndrome in Adults: NICE Quality Standard [QS114]* 2016. Available from URL: <https://www.nice.org.uk/guidance/qs114>.
- Halder SLS, Locke GR, Schleck CD, Zinsmeister AR, Melton LJ, Talley NJ. Natural history of functional gastrointestinal disorders: a 12-year longitudinal population-based study. *Gastroenterology.* 2007; **133**: 799–807, e1.
- Olafsdottir LB, Gudjonsson H, Jonsdottir HH, Thjodleifsson B. Stability of the irritable bowel syndrome and subgroups as measured by three diagnostic criteria – a 10-year follow-up study. *Aliment. Pharmacol. Ther.* 2010; **32**(5): 670–80.

## Supporting information

Additional supporting information may be found in the online version of this article at the publisher's website:

**Table S1.** Frequency table of the main concerns patients have regarding their gastrointestinal symptoms.