

## SPECIAL ISSUE ARTICLE

# The SYMPTOM-upper gastrointestinal study: A mixed methods study exploring symptom appraisal and help-seeking in Australian upper gastrointestinal cancer patients

Napin Karnchanachari<sup>1</sup>  | Shakira Milton<sup>1</sup> | Tjuntu Muhlen-Schulte<sup>2</sup> |  
Riati Scarborough<sup>2,3</sup>  | Jennifer F. Holland<sup>2</sup> | Fiona M. Walter<sup>1,4</sup> |  
John Zalberg<sup>2</sup> | Jon Emery<sup>1</sup>

<sup>1</sup>Department of General Practice, University of Melbourne, Melbourne, Victoria, Australia

<sup>2</sup>School of Public Health and Preventative Medicine, Monash University, Melbourne, Victoria, Australia

<sup>3</sup>Faculty of Veterinary and Agricultural Sciences, University of Melbourne, Melbourne, Victoria, Australia

<sup>4</sup>The Primary Care Unit, Department of Public Health and Primary Care, University of Cambridge, Cambridge, UK

## Correspondence

Napin Karnchanachari, University of Cambridge, Clare Hall, Herschel Road, Cambridge CB3 9AL, UK.

Email: [nnnapin186@gmail.com](mailto:nnnapin186@gmail.com)

## Abstract

**Objective:** There is limited evidence on the development of pancreatic and oesophagogastric cancer, how patients decide to seek help and the factors impacting help-seeking. Our study, the first in Australia, aimed to explore symptom appraisal and diagnostic pathways in these patients. A secondary aim was to examine the potential to recruit cancer patients through a cancer quality registry.

**Methods:** Patients diagnosed with pancreatic or oesophagogastric cancer were recruited through Monash University's Upper-Gastrointestinal Cancer Registry. Data collected through general practitioners (GP) and patient questionnaires included symptoms and their onset, whereas patient interviews focused on the patient's decision-making in seeking help from healthcare practitioners. Data collection and analysis was informed by the Aarhus statement. Coding was inductive, and themes were mapped onto the Model of Pathways to Treatment.

**Results:** Between November 2018 and March 2020, 27 patient questionnaires and 13 phone interviews were completed. Prior to diagnosis, patients lacked awareness of pancreatic and oesophagogastric cancer symptoms, leading to the normalisation, dismissal and misattribution of the symptoms. Patients initially self-managed symptoms, but worsening of symptoms and jaundice triggered help-seeking. Competing priorities, beliefs about illnesses and difficulties accessing healthcare delayed help-seeking.

**Conclusion:** Increased awareness of insidious pancreatic and oesophagogastric cancer symptoms in patients and general practitioners may prompt more urgent investigations and lead to earlier diagnosis.

Napin Karnchanachari is studying at the University of Cambridge and no longer works at the University of Melbourne. Dr Fiona M Walter currently works at the Barts and The London School of Medicine and Dentistry, Queen Mary University of London, United Kingdom.

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**KEYWORDS**

cancer registry, early diagnosis, gastric cancer, general practice, oesophageal cancer, pancreatic cancer

## 1 | INTRODUCTION

Upper gastrointestinal (UGI) cancer are cancers of the oesophageal, stomach, pancreatic, duodenal, gall bladder and bile duct, liver and small bowel. The SYMPTOM-UGI study focuses on pancreatic and oesophagogastric (OG) cancer. In Australia, pancreatic cancer has the highest mortality rate, with a 5-year survival rate of only 10.7%. Oesophageal and gastric cancers have a 5-year survival rate of 22.1% and 31.2%, respectively (Health, 2020). International evidence suggests time to presentation to a GP with symptoms and time to diagnosis for these cancers are longer than for more common cancers such as melanoma and breast cancers. U.K. studies have found upper gastrointestinal (UGI) cancer patients are often symptomatic for many months before presenting to a GP and are diagnosed at a later stage (Dregan et al., 2013; Keeble et al., 2014; Lacey et al., 2016; Neal, Din, et al., 2014).

In Australia, there is limited evidence on the onset and development of UGI symptoms which could herald pancreatic or OG cancer and how patients decide to seek help. Previous studies have investigated risk factors, quality of life post-diagnosis, interventions to reduce time to diagnosis and symptom management; however, these have collected only quantitative data (Adair et al., 2011; Burmeister et al., 2016; Emery et al., 2014; Smith et al., 2014; Smithers et al., 2010).

The SYMPTOM-UGI study uses mixed methods to explore symptom appraisal and diagnostic pathways in pancreatic and OG cancer patients. The qualitative aspect allows for nuanced understanding of the factors impacting help-seeking and diagnosis. Given the subtle nature of pancreatic and OG cancer symptoms, patient interviews provide much-needed insight on how patients perceive their symptoms and decide to seek help, which cannot be elucidated from quantitative data. Our secondary aim was to examine the potential to recruit cancer patients for studies of diagnostic pathways through Australia's first UGI cancer quality registry, the Upper Gastrointestinal Cancer Registry (UGICR).

## 2 | METHODS

### 2.1 | Study population

We recruited patients from Monash University's UGICR (Maharaj et al., 2019). The UGICR aims to identify variation in treatment and outcomes of individuals newly diagnosed with a primary cancer of the pancreas, oesophagus, stomach, liver or biliary system. Our study focused on pancreatic and OG cancer as UGICR data on pancreatic and OG cancer patients were most established at the time.

Information about pancreatic and OG cancer patients were obtained by Monash University researchers through the State-based Cancer Registry, the Victorian Cancer Registry (VCR); hospital medical records; clinician medical records; telephone; or email surveys; and then entered into the UGICR's database using REDCap electronic data capture tools hosted at Monash University (Harris et al., 2019, 2009).

Patients were eligible for the study if they were diagnosed with cancers of the oesophagus, pancreas or gastric in the previous 6 months and were diagnosed or treated at a participating UGICR hospital. Patients who opted out of the UGICR or needed an interpreter for medical appointments were excluded. Due to delays related to cases being received and processed by the VCR, 6 months was the closest to diagnosis we could recruit patients. Ethics was approved by Monash University's Health Human Research Ethics Low Risk Panel.

### 2.2 | Recruitment

Researchers from Monash University's UGICR identified and mailed eligible participants a letter of invitation and the SYMPTOM-UGI questionnaire with a reply-paid envelope. Non-responders were followed up twice (Figure 1). Participants were also given the option to complete the questionnaire over the phone with a researcher. Additionally, participants were invited to consent to an optional interview with SYMPTOM-UGI researchers. We also requested the patient's consent to contact their GP for information about relevant consultations and their symptoms.

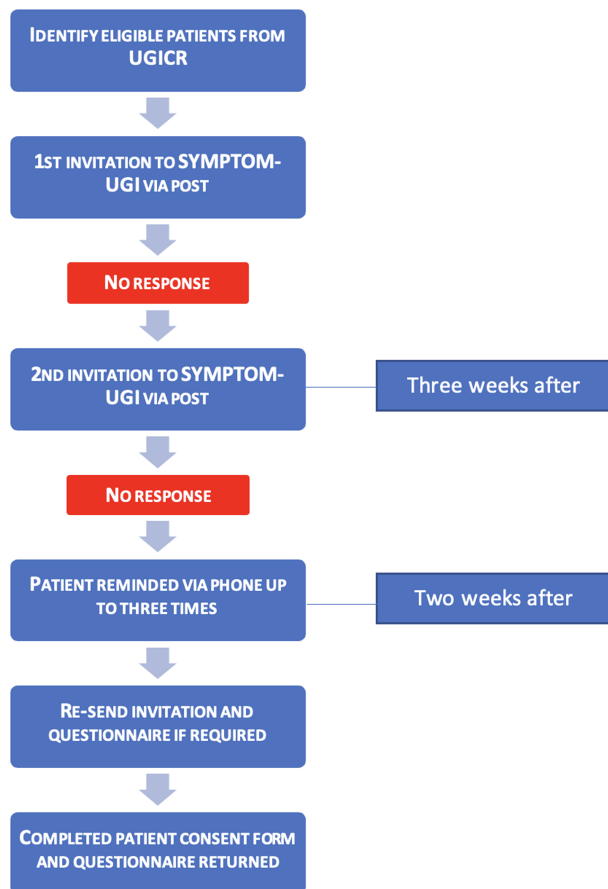
## 3 | DATA COLLECTION AND MANAGEMENT

### 3.1 | The UGICR

Data collected by the UGICR included gender, residential postcode, cancer type, staging at time of diagnosis and date of diagnosis. Hospital location of cancer diagnosis and treatment were also collected.

### 3.2 | SYMPTOM-UGI questionnaire

The SYMPTOM-UGI questionnaire is a modified version of a validated questionnaire from a previous SYMPTOM UK study (Walter et al., 2016). The questions explored the presence or absence of symptoms associated with UGI cancers, when it was first noticed by the participant, the duration of symptoms and estimated dates of presentation to a healthcare practitioner (HCP). The remaining sections



**FIGURE 1** Recruitment process of the SYMPTOM-UGI study

enquired about other symptoms, demographics, comorbidities and patient consent.

### 3.3 | Qualitative interviews

Participants consenting to an audio-recorded interview were contacted by SYMPTOM-UGI researchers for a semi-structured phone interview with NK or SM. Phone interviews allowed access to patients in remote areas, thus not limiting participants to metropolitan Melbourne or patients that are too unwell for travel or require rescheduling. Participants were asked about their first GP consultation, their symptoms and what prompted help-seeking. A topic guide was used covering key areas of exploration, including a list of open-ended questions, which led into subsequent questions, depending on the interviewee's answers.

### 3.4 | GP questionnaire

If the participant consented, a UGI cancer-specific questionnaire was mailed to the participant's GP to obtain dates of presentation, type and duration of UGI cancer's symptoms 12 months preceding diagnosis.

Referral date and date of first appointment with a specialist were also requested. A phone or e-mail reminder was sent after 1 month.

## 4 | THEORETICAL FRAMEWORK

We applied the Model of Pathways to Treatment to inform our data collection and analysis (Scott et al., 2013). We focused on Patient Interval (PI), Diagnostic Interval (DI) and Total Diagnostic Interval (TDI). PI is the time from first symptom onset to first presentation to an HCP. DI is the time from first presentation to an HCP to the date of diagnosis. The combination of PI and DI forms the TDI (Figure 2). Additionally, we explored the Primary Care Interval (PCI), the time between date of first GP appointment to date of referral (Weller et al., 2012).

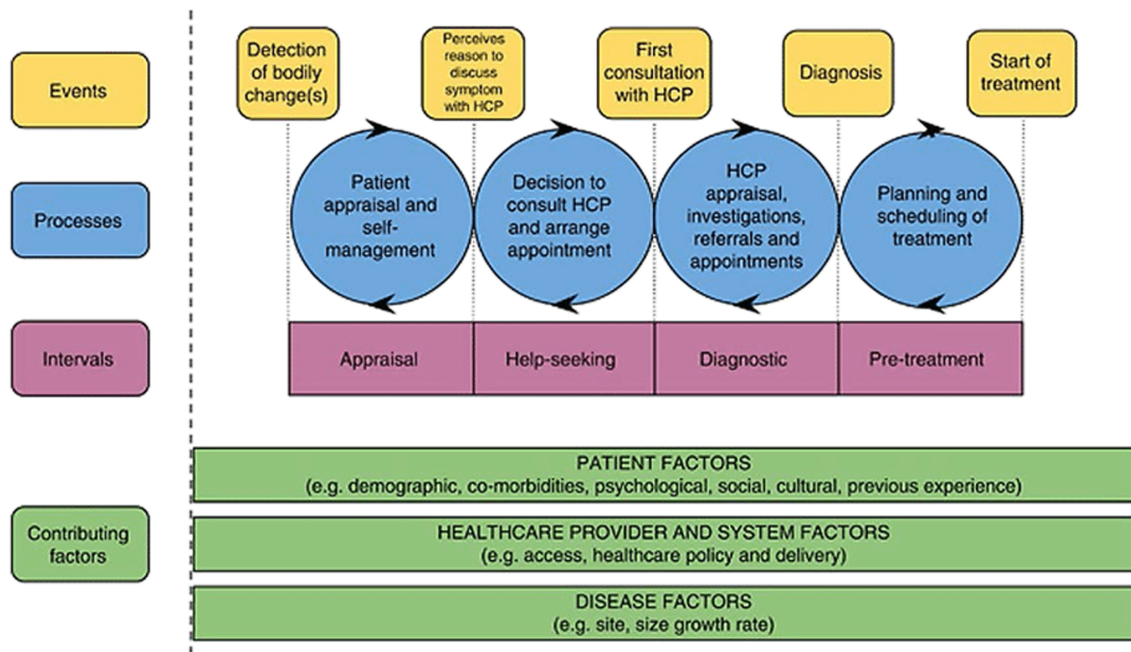
## 5 | DATA ANALYSIS

### 5.1 | Quantitative data

Where patient-reported dates from the SYMPTOM-UGI questionnaire were ambiguous, such that a range of dates were supplied, Cancer Symptom Interval Measure (C-SIM) midpoint rules were applied to estimate the date of first symptom onset and first presentation to an HCP (Neal, Nafees, et al., 2014). Where necessary, researchers (JE, SM, NK) triangulated data from the patient interview and questionnaire and GP questionnaire to estimate these dates. For instance, if the date of onset or presence or absence of a symptom reported in the patient questionnaire differed from the GP's questionnaire, interview transcripts were used to elucidate the most likely answer. For the PI, DI, TDI and PCI, their median, max, min and interquartile ranges (IQRs) were calculated with Microsoft Excel (2020) and rounded to two significant figures. Our small sample size precluded defining delayed help-seeking. We applied guidelines in the Aarhus statement to define key dates along the diagnostic pathway (Weller et al., 2012). This method of data integration allowed us to explore convergence and discrepancy of findings across types of data.

### 5.2 | Qualitative data

Interviews were audio-recorded, professionally transcribed verbatim and managed using NVivo12 software. Transcripts were analysed via thematic analysis; codes were first sorted into exhaustive groupings, then combined to create broader themes and mapped onto the Model of Pathways to Treatment (Scott et al., 2013). To ensure comprehensiveness, SM doubled-coded the first three transcripts. All coding was regularly assessed by two other researchers to discuss the interpretation of the transcripts and ensure consistency of coding. Furthermore, rather than solely focusing on data consistency, and trends, heterogeneity of responses were considered so as to not discount any deviant cases (Guba, 1981).



**FIGURE 2** Model of pathways to treatment

## 6 | RESULTS

### 6.1 | Sample

From November 2018 to March 2020, of 489 patients screened, 90 eligible patients were identified from the UGICR. Many patients were ineligible because their UGI cancer had been diagnosed more than 6 months before their data reached the UGICR.

Of the 90 eligible patients, 27 completed and returned the SYMPTOM-UGI questionnaire (30%). Participants included 20 pancreatic cancer patients and 7 OG cancer patients (4 gastric, 2 oesophageal and 1 gastro-oesophageal junction); 17 expressed interest in participating in the interview, and 13 interviews, lasting between 15 and 40 min, were completed. All 27 participants consented to the release of their GP records, and 22 of 27 (81%) GP questionnaires were returned.

When classifying patients' cancer staging as early or late, we used staging at time of diagnosis where available; otherwise, cancer stage at time of resection was used. There were 63 non-respondents: 10 (14%) early stage and 24 (38.0%) late stage cancer (staging data unavailable for 29 participants [46%]). Participant, healthcare and disease characteristics are presented in Table 1.

### 6.2 | Symptoms reported in the SYMPTOM-UGI questionnaire

All symptoms in the questionnaire (Figure S1) were reported at least once. The most common symptoms experienced in pancreatic patients were 'pain in the upper part of your stomach' and 'jaundice'. The

most common symptoms for OG cancer patients were 'stomach contents moving upwards to your throat or mouth' and 'unexplained weight loss'.

While recognising the small number of participants, the subgroup reporting jaundice were solely pancreatic cancer patients and had shorter PI, DI and TDI in comparison to those who did not report jaundice, of which a greater proportion were late stage patients (Table 2). Jaundice was also one of the most common symptoms in participants with shorter PI ( $\leq 16$  days) and DI ( $\leq 31$  days). In this small sample, there were no other clear patterns of symptoms in those with short versus longer intervals.

### 6.3 | PI, DI and TDI

Most participants reported a gradual onset of symptoms and were unable to recall precisely when they started; thus, dates were calculated using C-SIM rules to account for this uncertainty. Overall PI, DI and TDI for pancreatic and OG cancer are shown in Table 3; patients with pancreatic cancer had shorter PI, DI and TDI than OG cancer patients. PI and DI could not be calculated for two participants as dates provided were insufficient. One participant was excluded from calculations of PI, DI and TDI as their only reported symptom began 4 years prior to date of diagnosis and was unlikely to be related to their cancer diagnosis.

Of the 22 GP questionnaires received, 16 provided dates of referrals and specialist appointment (median PCI: 6 days, IQR: 26). Referrals were made to gastroenterology, surgical, respiratory and oncology; three were referred or presented directly to the emergency department.

**TABLE 1** Participant characteristics

	Survey participants (n = 27)	Interview participants (n = 13)
Age (years)		
Median (range)	72 (54–89)	68 (55–84)
Sex		
Male n (%)	19 (70)	8 (61)
Female n (%)	8 (30)	5 (39)
Cancer type		
OG n (%)	7 (26)	3 (23)
Pancreatic n (%)	20 (74)	10 (77)
Cancer stage at time of diagnosis		
Staging unknown n (%)	5 (19)	4 (31)
Early (stages I and II) n (%)	12 (44)	4 (31)
Late (stages III and IV) n (%)	10 (37)	5 (38)
Ethnic group/racial group		
Australian n (%)	15 (56)	9 (69)
European n (%)	8 (30)	3 (23)
African n (%)	2 (7)	1 (8)
Asian n (%)	2 (7)	0
Co-morbidities		
Lung disease n (%)	2 (8)	1 (7)
Heart disease n (%)	5 (20)	2 (14)
Anxiety or depression n (%)	4 (16)	2 (14)
Cancer (other than oesophageal, stomach or pancreatic) n (%)	4 (16)	2 (14)
Peptic ulcer n (%)	1 (4)	1 (7)
Arthritis n (%)	6 (24)	4 (29)
Barrett's oesophagus or reflux disease n (%)	3 (12)	2 (14)
Educational qualifications		
None n (%)	1 (4)	0
Primary school n (%)	2 (7)	1 (8)
Secondary school n (%)	10 (37)	5 (38)
Tertiary education n (%)	13 (48)	7 (54)
Other n (%)	1 (4)	0
Living situation		
Alone n (%)	10 (37)	4 (31)
With others n (%)	17 (63)	9 (69)
Residential postcode <sup>a</sup>		
Rural n (%)	8 (30)	5 (38)
Metropolitan n (%)	19 (70)	8 (62)
Diagnosis—metropolitan/regional hospital		
Metropolitan n (%)	26 (96)	12 (92)
Regional n (%)	1 (4)	1 (8)
Diagnosis—public/private hospital		
Public n (%)	24 (89)	12 (92)
Private n (%)	3 (11)	1 (8)

<sup>a</sup>Rurality was calculated using the Department of Agriculture website (Department of Agriculture, 2019).

**TABLE 2** PI, DI and PCI and cancer staging for patients reporting jaundice versus patients not reporting jaundice

	Jaundice reported (n = 11)	Jaundice not reported (n = 16)
PI (median days)	14	42
DI (median days)	10	45
PCI (media days)	4	28
Early (stages I and II) n <sup>a</sup>	7	5
Late (stages III and IV) n <sup>b</sup>	1	9

<sup>a</sup>Staging unknown for 3 participants.

<sup>b</sup>Staging unknown for 2 participants.

**TABLE 3** Median of PI, DI and TDI for patients diagnosed with pancreatic and OG cancer

	Pancreatic cancer	OG cancer	Overall
PI (days)	14 (n = 18) IQR: 45	61 (n = 5) IQR: 35	16 (n = 23) IQR: 68
DI (days)	26 (n = 19) IQR: 77	74 (n = 5) IQR: 95	31 (n = 24) IQR: 80
TDI (days)	34 (n = 18) IQR: 138	189 (n = 5) IQR: 72	92 (n = 23) IQR: 163

## 7 | QUALITATIVE RESULTS

Five overall themes emerged from our interviews. Each theme is illustrated with verbatim quotations in Table 4. PI and DI are provided for quotations relating to events prior and after to participants' first GP appointments, respectively.

### 7.1 | Theme 1: Symptom awareness and initial symptom appraisal

Most participants reported limited awareness of pancreatic and OG cancer symptoms, while few were more informed or compared it to better known symptoms of other cancers. Lack of symptom awareness led participants to normalise, dismiss or misattribute them. Competing priorities, such as being a caretaker, also meant some participants noticed symptoms but were too mentally preoccupied to pay them attention (Table 4 [1.]).

### 7.2 | Theme 2: Responses to initial symptom appraisal

Many of the participants felt their symptoms were minor enough to self-manage through lifestyle changes. Notably, participants who did not self-manage their symptoms had shorter PI (median 10 days vs. 88 days) and DI (median 5 days vs. 31 days) (Table 4 [2.]).

**TABLE 4** Quotes illustrating each theme

## 1. Symptom awareness and initial appraisal of symptoms

Comparison with symptoms of other cancers	‘I think with the stomach [cancer], well you know, yeah, what are the symptoms? [...] Like breast cancer, if there's a lump or tenderness or tingling, you know you better go and have that checked. But with stomach cancer, I don't know, I don't know how you explain it’ (S46: female, age 73, early stage OG cancer, 90-day PI).
Lack of symptom awareness	‘I think had I been more aware of the initial symptoms of pancreatic cancer I might have put together the fatigue and weight loss that I was experiencing. I might have just thought - even though I was attributing those to other things - It might have occurred to me to mention it to the doctor’ (S80: female, age 59, pancreatic, no staging recorded, 88-day PI).
More symptom awareness	‘From what I have read it's been - It [pancreatic cancer] doesn't always present with particularly strong symptoms until it's too late [...] it's quite a mysterious illness because it seems like it varies for everybody’ (S75: female, age 63, late stage pancreatic cancer, 183-day PI).
Normalising and dismissal of symptoms	‘I experienced unusual tiredness which I attributed at the time to high work commitments and at times I was doing extra work’ (S80: female, age 59, pancreatic, no staging recorded, 88-day PI). ‘At the time I was that busy with my wife and I didn't take much notice of it [symptoms] and that sort of thing’ (S29: male, age 68, pancreatic, no staging recorded, 95-day PI).
Misattribution of symptoms	‘I've always had a bad back. I've got three prolapsed discs so that's [unexplained back pain] a hard one to distinguish between’ (S307: male, age 56, early stage OG cancer, PI unable to be calculated). ‘As a kid I had nephritis, and the first sign of that of course is darkening of the urine’ (S73: male, age 57, early stage pancreatic cancer, 5-day PI).

## 2. Responses to initial symptom appraisal

Dietary changes	‘I managed what I ate and when I ate and how I ate it that I could reduce the symptoms [stomach pain]. So, I would eat very lightly. I'd have a healthy but light meal in the middle of the day and generally at night just have a bowl of soup or something that was easy to digest’ (S75: female, age 63, late stage pancreatic cancer, 183-day PI).
Managing medication	‘You can't start messing around with the amount of insulin you have, but I had to do that to try to get the [blood sugar] readings somewhere near reasonable’ (S6: male, age 76, pancreatic, no staging recorded, diabetic, 1-day PI).
Role of others in symptom appraisal	Interviewer: ‘Did you discuss your symptoms with anyone other than your doctor?’ Participant: ‘Only my wife’ (S265: male, age 69, late stage pancreatic, 1-day PI). Participant: ‘I think I told my son that I was feeling lousy, but you know, well - you can't make a big thing out of it, can you? [...] well, I just told him I'm just not feeling the best, but that's about as far as it went’ Interviewer: ‘Did he encourage you to seek medical advice?’ Participant: ‘No, no, were not like that’ (S6: male, age 76, pancreatic, no staging recorded, 1-day PI). ‘[M]y wife was going through cancer at the same time. I didn't know I had it. One of the public care nurses told me to see a doctor because I was going yellow and she didn't like the look of it [...] she made sure I went and seen the doctor the next day, or that day’ (S29: male, age 68, pancreatic, no staging recorded, 95 days PI) ‘My wife said I was jaundiced’ (S265: male, age 69, late stage pancreatic, 1-day PI).
Personal preference to not speak about their health	‘I'm not someone to talk about my health and I didn't really contemplate it could be anything serious’ (S75: female, age 63, late stage pancreatic cancer, 183-day PI).

## 3. Further appraisal of symptoms

Abnormal symptoms	‘The fatigue was that pronounced, but I pushed through it. Then I'd get home and then I'd fall on the couch and fall asleep, into a deep sleep for an hour or so. Very unlike me’ (S75: Female, age 63, late stage pancreatic cancer, 183-day PI) ‘I was eating, and instead of enjoying eating, I was getting pains in my stomach through eating [...] It could last for a whole - a couple of hours’ (S6: Male, age 76, pancreatic, no staging recorded, 1-day PI)
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TABLE 4 (Continued)

Sequential symptom onset	<p>'I got an itchy skin. There was no rash, but the skin was all itchy [...] over that weekend I vomited at night-time - a couple of nights and the urine changed to a very bright golden colour. So, I knew something was wrong when the urine was so bright'</p> <p>(S39: female, age 73, early stage pancreatic cancer, 14-day PI)</p>
Generally feeling unwell	<p>'I knew I was sick, so. I just didn't - I didn't quite know how [to describe it]'</p> <p>(S73: male, age 57, early stage pancreatic cancer, 5-day PI)</p> <p>'I felt for some reason there was some underlying problem'</p> <p>(S75: female, age 63, late stage pancreatic cancer, 183-day PI)</p>
Disconnected attitude towards family history of cancer	<p>'Apparently my sisters had - my eldest sister had breast cancer, but she got over that'</p> <p>(S6: male, age 76, pancreatic, no staging recorded, 1-day PI)</p> <p>'Well, not that I've discussed the details, but I had an older sister who did die of pancreatic cancer'</p> <p>(S488: male, age 72, early stage pancreatic, 7-day PI)</p> <p>'my twin brother died three years ago, he was rushed off to the Dandenong Hospital and they discovered a tumour in his bowel [...] our destiny is, I believe its mapped out for us and we have no control over any of that'</p> <p>(S46: female, age 73, early stage OG cancer, 90-day PI).</p>
<b>4. Help-seeking</b>	
Delays due to competing priorities	<p>'Probably if [wife] hadn't have been sick I might have done something, gone to the doc a bit earlier'</p> <p>(S29: male, age 68, pancreatic, no staging recorded, 95-days PI).</p> <p>'So yeah, there would have been a follow up [with the GP], but I never got back because we ended up, I think about three weeks later we ended up going to - or month later we ended up going [on vacation]'</p> <p>(S46: female, age 73, early stage OG cancer, 90-day PI).</p>
Personal beliefs led to delays in help-seeking but not always	<p>'I'm not someone who has ever gone to the doctor much and just a regular thing [...] I hardly ever went to the doctor[...]there's a lot of women like me who are stoic, who - oh just get on with it and it mightn't be anything much'</p> <p>(S75: female, age 63, late stage pancreatic cancer, 183-day PI).</p> <p>'Yeah, I don't want to be running [to the GP] - the doctors are busy enough now'</p> <p>(S46: female, age 73, early stage OG cancer, 90-day PI).</p> <p>'Well, you don't like going to the doctors, do you, because you might find out something that you don't particularly want to hear'</p> <p>(S6: male, age 76, pancreatic, no staging recorded, 1-day PI).</p>
Inability to access healthcare	<p>'it [altered urine colour] happened on the Sunday and I went to ring the doctor on the Monday, and I couldn't get in [to the GP] until the Tuesday'</p> <p>'Because they were trying to get me down to Melbourne but there [were] no beds for the surgery'</p> <p>(S39: female, age 73, early stage pancreatic cancer, 14-day PI).</p> <p>'It [vomiting] came on very quickly on the Sunday. Well, so probably Saturday which - the GPs aren't open at the weekend so just a matter of going straight to Accident and Emergency'</p> <p>(S265: male, age 69, late stage pancreatic, 1-day PI)</p>
Sudden onset of pain triggering help-seeking	<p>'I had this pain in the middle of the night, sort of all my stomach, right around and I called the ambulance and they took me to the hospital'</p> <p>(S88: female, age 84, pancreatic, no staging recorded, unable to calculate PI).</p>
Altered urine colour triggering help-seeking	<p>'That [altered urine colour] only happened over the weekend, probably the Sunday before I got to the doctor'</p> <p>(S39: Female, age 73, early stage pancreatic cancer, 14-day PI).</p>
Attending HCP appointment for other reasons	<p>'The doctor was testing me for something completely different, and something didn't look right and so he ordered an ultrasound, and that's where they picked up lesions in the liver [...] It was a totally accidental find'</p> <p>(S32: male, age 67, late stage pancreatic cancer, 6-day PI).</p> <p>Participant: 'my kidneys weren't right - they - actually, in the hospital, I was in the hospital for a month, and most of the time I spent getting my kidneys back in order'</p> <p>Interviewer: 'when you went into the hospital at the end of June, you went because of you're off [blood sugar level] readings and your kidneys, not because of the cancer, right?'</p> <p>Participant: 'I think so, yes. I think so. Because the doctor told me she - after she got the blood test back, she said I want you in hospital, and I want you in hospital now'</p> <p>(S6: male, age 76, pancreatic, no staging recorded, 1-day PI).</p>

(Continues)

TABLE 4 (Continued)

5. Factors impacting time to diagnosis after help-seeking	
Omitted telling GP about symptoms	'I didn't mention the weight loss or the fatigue [...] Because I didn't associate them with the abdominal symptoms' (S80: female, age 59, pancreatic, no staging recorded, 122-day DI).
GP dismissal of symptoms	'I went to my doctor and had always seen me like a star patient in terms of oh, [She's] no worries, she's out there, she's fit, she's always been' (S75: female, age 63, late stage pancreatic cancer, 82-day DI). 'He [GP] didn't sort of think much about it [bile at the back of the throat]. Yeah. Didn't know whether it was to do with the asthma or what, but yeah, nothing sort of was done any more about that' (S29: male, age 68, pancreatic, no staging recorded, 91-day DI).
Pushing for further investigations	'I said look I think I really have to have this investigated further through a CT scan. He [GP] said oh look that's unnecessary, radiation and all that and I said, no, I'm sick; there's something wrong here [...] So I had that done and then that was the first to reveal that there was something nasty present in the pancreas' (S75: female, age 63, late stage pancreatic cancer, 82-day DI). 'I was away for four weeks and soon as I got back, we started pushing [for an endoscopy]' (S307: male, age 56, late stage OG cancer, DI unable to be calculated).
Organisational delays	'it actually took three or four months for them to actually organise to stick the camera down my throat and have a look' (S307: male, age 56, late stage OG cancer, PI could not be calculated).
Lack of coordination between healthcare services	'it actually took three or four months for them to actually organise to stick the camera down my throat and have a look' (S307: male, age 56, late stage OG cancer, PI could not be calculated).

Some participants chose not to discuss their symptoms with family and friends, as to not upset them or did not deem the symptoms serious enough to discuss. Few participants did, but these discussions seldom led to encouragement to seek medical advice. This is perhaps because pancreatic and OG cancer symptoms are often subtle and did not cause alarm. Jaundice was often noticed by others, such as a family member or an HCP when they attended an appointment for other reasons.

### 7.3 | Theme 3: Further appraisal of symptoms

All participants began to take more notice of their symptoms when they persisted or progressively got worse, such as persistent or worsening abdominal pain. Participants also described a general feeling of being unwell but did not know how to describe it (Table 4 [3.]).

Participants spoke about their family history of cancer in a disconnected manner, including ideals of a predetermined destiny and a resigned attitude towards their cancer diagnosis. None explicitly expressed concerns about their own risk of developing cancer in relation to their family's cancer history or that it prompted them to seek advice from an HCP.

### 7.4 | Theme 4: Delays and triggers in help-seeking

Participants cited personal beliefs and habits around help-seeking for their delay in speaking to a GP about their symptoms. Difficulty in

securing an appointment with the GP or feelings that the GP were too busy also delayed help-seeking (Table 4 [4.]).

Help-seeking was often triggered by abdominal pain, and symptoms of jaundice, such as altered urine colour or pale stools. However, participants with abdominal pain had longer PIs (median: 88 days) than participants with altered urine colour and pale stools (median: 7 days) as less severe abdominal pain may have been dismissed as indigestion. Symptoms of jaundice usually led to prompt help-seeking and immediate investigations, as reflected in the short PCI. Unlike participants who sought help for their symptoms, some participants saw a GP for monthly check-ups, or tests for other conditions, and their cancer was diagnosed incidentally. One participant reported fear of going to see the GP and finding out 'bad news'; however, they had a short PI (1 day). This demonstrates a fear of potential diagnoses but not to the extent that hinders help-seeking.

Rural participants ( $n = 8$ ) had longer PI and DI than metropolitan participants (median 55 vs. 15 PI; median 41 vs. 31 DI). Interview transcripts of rural participants ( $n = 5$ ) demonstrated rural patients often had to drive to metropolitan hospitals for further testing or treatment.

### 7.5 | Theme 5: Factors impacting time to diagnosis after help-seeking

Although participants eventually sought help, lack of pancreatic and OG cancer symptom awareness meant participants omitted telling their GP about some symptoms. Despite an overall PCI median of 6 days, some participants ( $n = 4$ ) reported their symptoms were



dismissed or misattributed by their GP, leading to a longer median DI (>31 days). When GPs dismissed symptoms, some participants pushed for further investigations, but others trusted and followed their long-term GP's guidance. However, some patients with long-term GPs also pushed for further testing, perhaps due to the rapport and ease found with long-term GPs (Table 4 [5.]).

A patient who had been previously diagnosed with a different cancer also pushed for further testing, as they were possibly more familiar with the diagnostic process and were comfortable in asking for further testing. This suggests that patient factors—such as assertiveness and health literacy—as well as the relationship between the patient and their GP impacted the patients' behaviour. Further research is warranted to identify modifiable patient and relationship factors that could reduce diagnostic delays. Additionally, participants reporting a lack of coordination between healthcare services felt that this contributed to a longer diagnostic interval.

## 8 | DISCUSSION

This study aimed to use data from multiple sources to explore patient and HCP symptom appraisal, as well as factors related to longer PI and DI in pancreatic and OG cancer patients. Our secondary aim was to examine the feasibility of recruiting patients with UGI cancers from a cancer quality registry into studies about diagnostic pathways.

Limited awareness of pancreatic and OG cancer symptoms led to normalisation, dismissal and misattribution of symptoms. Participants often reported a gradual worsening of abdominal pain and discomfort, and help was only sought when pain persisted for weeks to months or if it became acutely severe. Lack of symptom awareness also meant some participants omitted telling their GPs about their symptoms. Many participants, especially those with OG cancer, experienced symptoms for a long period before seeking help. Shorter PIs were mainly in pancreatic cancer patients presenting with jaundice. This is to be expected given that jaundice is the only symptom that is strongly predictive of pancreatic cancer (Stapley et al., 2012). Delays in help-seeking were also a result of self-management strategies and competing priorities. In contrast with previous findings (Mills et al., 2017), when symptoms were discussed with friends and family, few led to encouragements to seek help with a GP, and family history of cancer did not prompt help-seeking. Attitudes towards life also contributed to delays in help-seeking, including participants not wanting to talk about their health or a fatalistic attitude towards cancer.

Some participants felt their GP's appraisal of their symptoms was influenced by their perception of that patient from previous consultations. This sometimes led GPs to dismiss symptoms as minor or misattribute them to other conditions. Furthermore, organisational issues and miscommunication between healthcare services led to difficulties in accessing healthcare. For our secondary aim, we were able to recruit newly diagnosed pancreatic and OG cancer patients through Australia's first UGI cancer clinical quality registry, the UGICR.

### 8.1 | Strengths and limitations

The main limitation of this study is our overall recruitment and response rates. We had hoped to recruit participants soon after diagnosis; however, the processes before a patient is enrolled into the UGICR meant recruitment occurred several months after diagnosis. Comparisons with the total UGICR cohort suggest patients with earlier stage disease at the time of recruitment were overrepresented in our sample, impacting the comprehensiveness of our account.

Our small sample size ( $n = 27$ ) limited our abilities to make statistical comparisons regarding patient characteristics, pathways to treatments and the length of the intervals. We had hoped to explore subtle differences in symptom appraisal and help-seeking between pancreatic and OG cancer; however, our small sample of OG cancer patients hindered this. Although low, our response rates are higher than similar U.K.-based studies in this patient population, reflecting the challenges of recruiting patients who are often undergoing major treatments or too unwell to respond (Neal, Din, et al., 2014; Smith et al., 2014; Smithers et al., 2010). As patients were recruited within 6 months of diagnosis, recollection about their symptoms and healthcare experience may have been impacted by post-hoc rationalisation and recall bias. To assist participants with their recall and reduce bias, interviewers used events in the participant's life to create a timeline of their experiences and triangulated data from the GP, patient questionnaire and interviews.

Similar studies completed face-to-face interviews, whereas we conducted ours by telephone (Humphrys et al., 2020; Mills et al., 2017; Whitaker et al., 2015). Telephone interviews pose greater difficulties in building rapport and offering emotional support; however, they may create a less intimidating environment, allowing the participant to speak more freely (Novick, 2008; Vogl, 2013).

A major strength of our study are the multiple data sources used to gather information about individual diagnostic pathways. Data collection and analysis was supported by two well-established research frameworks: the Aarhus statement and the Model of Pathways to Treatment (Scott et al., 2013; Walter et al., 2012; Weller et al., 2012). By recruiting through the UGICR, patients from multiple Victorian hospitals were recruited, ensuring a broad range of experiences, including people from regional and metropolitan areas who had been treated in public or private health services. The diversity of our participants allows generalising to the broader Australian population and not just to the state of Victoria.

### 8.2 | Comparisons with existing research

To our knowledge, this is the first study to investigate how symptoms of pancreatic and OG cancer are initially appraised by patients in Australia and what factors impact help-seeking and diagnosis. A previous Australian study on management of UGI cancer symptoms only used quantitative data from an HCP's perspective through medical records and cancer registries (Smithers et al., 2010). Our study collected quantitative and qualitative data from both HCPs and patients.

Patients and clinicians may perceive symptoms differently; thus, self-reported patient data are essential in understanding the patients' experience of their symptoms and help-seeking.

The largest international study on which this study was based was the U.K.'s SYMPTOM-Pancreas study (Walter et al., 2016). Consistent with our findings, U.K. studies also highlighted the subtle nature of early symptoms, which were normalised, until they progressed to more severe symptoms, such as persistent pain and jaundice, which triggered help-seeking. Furthermore, they also found that despite abdominal pain being the most common help-seeking trigger, help-seeking was often delayed due to its attribution to 'normal' indigestion (Humphrys et al., 2020; Mills et al., 2017). An Italian and Nepalese study reported self-medication to treat indigestion, which was associated with longer time to presentation, diagnosis and treatment (Dulal et al., 2020; Gobbi et al., 2013). In our study, however, patients tried alleviating their symptoms by changing their diet rather than taking medication.

Despite previous findings that social support plays an important role in help-seeking (Mills et al., 2017), this did not emerge as a theme from our interviews. Furthermore, they reported family history of cancer impacted the participant's decision to seek medical help, but our participants seemed unconcerned by their family history, and it did not affect their help-seeking. One patient reported one's destiny, including a cancer diagnosis, is predetermined, indicating a fatalistic attitude. Studies have shown cancer can be seen as destiny or the will of God, which can be a barrier to screening, diagnosis and treatment (Flórez et al., 2009; Powe & Finnie, 2003).

In a study of symptomatic patients in whom a cancer diagnosis had not been made (Whitaker et al., 2015), they identified help-seeking due to 'instinct', aligning with our findings of help-seeking due to unsettling 'gut feelings'. Patients in both studies felt GPs were busy and did not want to waste their GP's time with subtle symptoms. This echoes the idea of a 'good' patient, one that presents with 'serious' rather than manageable symptoms (Campbell et al., 2015; Proulx & Jacelon, 2004). This attitude may have contributed to some patients not asking for additional testing when they had a bad 'gut feeling'.

Although our findings are similar to findings from the United Kingdom, the United Kingdom has a population double that of Australia, in an area that is 50 times smaller. Although most people live in major Australia cities, some, including Indigenous Australians, live in rural and remote locations. Rural patients may experience longer PI and DI in comparison to metropolitan patients and often had to drive long distances for diagnostic assessment and treatment. Our study, albeit small, is the much-needed starting point for research into the patient experience of pathways to help-seeking and diagnosis in pancreatic and OG cancer patients.

### 8.3 | Implications for research and practice

Little is known about symptom onset and pathways to help-seeking and diagnosis in Australian pancreatic and OG cancer patients. Our

findings highlight factors influencing symptom appraisal and help-seeking and their impact on time to diagnosis. Lack of patient awareness of cancer symptoms identified an educational gap, which could be addressed through targeted symptom awareness campaigns.

Our findings suggest patients presenting with jaundice are investigated promptly. GP education to increase awareness of more subtle and non-specific pancreatic and OG cancer symptoms, such as indigestion, could prompt earlier investigations and diagnosis. Diagnostic uncertainty resulting from non-specific symptoms could be alleviated through symptom monitoring and a lower threshold for asking patients to return for review and timely follow-up (Almond et al., 2009).

We have examined the feasibility of recruiting patients through the UGICR and successfully recruited newly diagnosed pancreatic and OG cancer patients. Registries such as the UGICR provide much needed real-world evidence beyond the patient's basic demographic characteristics, including location (rural or metropolitan) of diagnosis and treatment, cancer stage at diagnosis and resection, comorbidities and the patients' postcode to determine rurality. Although our small sample size limited our ability to investigate whether these characteristics were related to longer or shorter intervals, the availability of such information demonstrates the potential of using a cancer quality registry in future research to better understand a cancer patient's diagnostic pathway. However, depending on the way the registry identifies potential participants, the timeliness of this method of recruitment in relation to the date of diagnosis may be an issue.

Future studies could focus on oesophageal, gastric and pancreatic cancer separately in larger cohorts, to explore barriers and enablers to early diagnosis and improve understanding of reasons for late presentation to GPs. This would provide further evidence for interventions such as public health messages and education to GPs. As many patients with UGI cancers present with late stage disease, the identification of accurate biomarkers to improve early detection, particularly for patients with non-specific symptoms is vital, however remains elusive (Rubin et al., 2018). In the meantime, we need to better understand the diagnostic pathways from a patient and health system perspective to inform approaches to detect these cancers earlier.

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### CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

### PERMISSION TO REPRODUCE MATERIAL FROM OTHER SOURCES

Figure 2 was reprinted from The Andersen Model of Total Patient Delay: a systematic review of its application in cancer diagnosis, Walter FM, Webster A, Scott S, Emery J, with permission from Dr Fiona M Walter.

## DATA AVAILABILITY STATEMENT

The authors confirm that the data supporting the findings of this study are available within the article and/or its supplementary materials.

## ORCID

Napin Karnchanachari  <https://orcid.org/0000-0003-2816-8983>

Riati Scarborough  <https://orcid.org/0000-0002-7021-0893>

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