





Psychological distress and bowel cancer screening participation

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Abstract

Objective: To better understand barriers to participation in mail-out bowel cancer screening programs, two survey studies tested the relationship between psychological distress and self-reported bowel cancer screening.

Methods: First, a nationally representative sample of Australians $N = 5421$ completed measures of bowel cancer screening and psychological distress (using the Kessler Psychological Distress Scale; K10). Second, $N = 479$ completed a survey measuring participation in the National Bowel Cancer Screening Program (NBCSP) and psychological distress using the Depression, Anxiety and Stress Scale. In both studies, logistic regressions were conducted to test relationships between psychological distress and self-reported screening participation.

Results: Study one found that psychological distress had a significant quadratic effect on having ever screened for bowel cancer, where screening rates were similar for those with low, moderate, or high levels of distress, but were lower for those with very high levels of distress. In study two, depression scores had a negative linear relationship with NBCSP participation (higher depression levels were associated with lower screening participation), and anxiety had a quadratic effect whereby NBCSP participation rates were higher with increasing levels of anxiety except in the severe category, where participation was significantly lower.

Conclusions: Findings indicate that psychological distress has a complex relationship with screening, and those with extreme levels of distress consistently show lower participation rates. Special efforts to encourage screening may be required for those experiencing extreme psychological distress and mental health disorders.

KEYWORDS

anxiety, bowel, cancer, colorectal, depression, faecal occult blood testing (FOBT), oncology, psycho-oncology, screening, stress

1 | BACKGROUND

Internationally, bowel cancer is responsible for approximately 935,000 deaths each year and is the second leading cause of cancer death following lung cancer.¹ The implementation of population-wide

bowel cancer screening programs substantially reduces bowel cancer-related mortality and disease burden. For instance, in the Australian National Bowel Cancer Screening Program (NBCSP), citizens aged 50–74 years are mailed a faecal occult blood test (FOBT) screening kit to be completed in their home once every two years.

Implementation of the NBCSP has led to earlier diagnoses, fewer cancer related complications, and improved survival rates.² However, the efficacy of such programs is hampered by poor participation rates. Currently, less than 44% of invited kit recipients take part in the Australian NBCSP.^{3,4}

A growing body of research exists concerning the barriers to bowel cancer screening participation. Accruing evidence has identified multiple barriers that prevent individuals from participating in potentially life-saving screening programs.^{5–8} Studies consistently find that forgetting or misplacing the kit, having concerns about hygiene, and the psychological distress associated with a positive test result are common barriers to screening participation.^{5,6}

People with heightened levels of psychological distress (global, subjective non-specific negative affect state that might encompass stress, anxiety, or depression⁹;) may be more susceptible to barriers that prevent bowel cancer screening participation via several mechanisms.¹⁰ For example, heightened depression can lead to pessimistic outcome expectancies¹¹ and lower self-efficacy,¹² these in turn may increase barriers to screening, such as avoidance or perceived physical difficulties in home bowel cancer screening. Similarly, heightened anxiety often results in an avoidance of situations that trigger disgust or fear.¹³ Those with higher levels of anxiety may be more prone to experience hygiene concerns about screening or be more fearful of a positive result. Stress, and the multiple conflicting priorities that it represents, may lead to distraction and neglect for healthcare. Stress may make people feel overwhelmed by screening, and thus less likely to invest the time and mental capacity to complete the kit.

Mixed findings exist on the relationship between psychological distress and bowel cancer screening participation. In qualitative research, participants often report that anxiety relating to a positive result or other life stressors prevent them from partaking in cancer screening^{5,14}; however, it is also reported that stress can motivate participation to reduce anxiety over a cancer diagnosis and seek reassurance of their health.¹⁵ Interestingly, while there are no studies to date on the nature of the relationship between anxiety or stress and mail-out bowel cancer screening, one study on bowel cancer screening via flexible sigmoidoscopy suggested state anxiety was related to both perceived threat of disease (associated with higher screening participation) and appraisal of greater barriers to bowel cancer screening (associated with lower screening participation).¹⁶ Another study found a positive relationship between high psychological distress (measured using the K6) and engaging in cancer screening before the recommended age.¹⁷ Further, lower levels of optimism has been associated with *higher* rates of bowel cancer screening via colonoscopy¹⁸; however, higher levels of depression have been associated with lower prostate cancer screening¹⁹ and lower breast cancer screening.²⁰ Together these findings might suggest a complex, potentially nonlinear relationship between psychological distress and bowel cancer screening. For example, low and high levels of distress may result in a lower likelihood of completing the kit, while moderate levels of distress may lead to a higher likelihood of kit return, indicative of a quadratic effect.

A greater understanding of the functional relationship between psychological distress and bowel cancer screening provides necessary insight for health interventions aiming to increase screening participation. Therefore, the aim of the current study is to examine the relationships between psychological distress (modelling both linear and non-linear relationships) and participation in bowel cancer screening using data from two sources applying different validated measures of psychological distress. The first study utilises a measure of overall psychological distress using the K10.²¹ To compliment this and drill down into specific facets of distress, the second study measures components of psychological distress including depression, anxiety, and stress using the DASS-21.²² Given the literature suggests that both low and high anxiety are associated with poorer screening behaviour,^{14–16} we predicted that psychological distress would demonstrate a quadratic effect on screening, whereby people with particularly low or extreme levels of distress would be less likely to screen for bowel cancer. We predicted this quadratic relationship would exist for overall psychological distress, as well as anxiety, stress, and depression.

2 | STUDY ONE: EXAMINATION OF POPULATION HEALTH SURVEY DATA

2.1 | Method

2.1.1 | Data source

Data were obtained from the 2014–2015 Australian National Health Survey.²³ The survey comprises a computer assisted telephone interview capturing a range of health-related measures in a representative sample of randomly selected Australian households. The stratified sampling design ensured that individuals from varying levels of remoteness across all states and territories within Australia took part in the survey. One adult (i.e., 18 years or older) was surveyed from each selected household ($N = 14,560$), and participation was non-voluntary. Access and use of these data for the specific purposes of this study was granted by the Australian Bureau of Statistics (ABS) based on approval from the university's Human Research Ethics Committee (ref. H20REA282). Non-missing responses to the relevant measures from adults between the ages of 50 and 74 were retained for this study ($N = 5421$). Further details on recruitment and sampling procedures are publicly available on the ABS website.²⁴ The mean age of the sample was 61.89 years ($SD = 6.92$). Demographic characteristics of this sample are detailed in Table 1.

2.2 | Measures

Basic demographic information was collected from each participant including age, sex, country of birth, language spoken at home, relationship status, and highest level of education. Bowel cancer screening

TABLE 1 Characteristics of the national health survey sample (N = 5421)

	n	%
Sex		
Male	2514	46.4%
Female	2907	53.6%
Relationship		
In a registered marriage	2890	53.3%
In a de facto marriage	180	3.3%
Not married	2351	43.4%
Remoteness		
Major cities	3374	62.2%
Inner regional	1167	21.5%
Other	880	16.2%
Area-level SES		
Quintile 1 (lowest)	1136	21.0%
Quintile 2	1131	20.9%
Quintile 3	1064	19.6%
Quintile 4	1004	18.5%
Quintile 5 (highest)	1086	20.0%
Country of birth		
Australia	3703	68.3%
United Kingdom	608	11.2%
New Zealand	136	2.5%
Southern and Eastern Europe	169	3.1%
Other	805	14.8%
Highest level of education		
University degree	1031	19.5%
Certificate or Diploma	1939	36.6%
Year 12	463	8.7%
Year 11	247	4.7%
Year 10 or below	1624	30.6%

was self-reported using a single item: "Have you ever tested for bowel cancer" with three response options including i) yes, tested for bowel cancer in the last 2 years, ii) yes, tested for bowel cancer, but not in the last 2 years, and iii) no, never tested for bowel cancer. Psychological distress was measured using the 10-item Kessler Psychological Distress Scale (K10), for which participants responded to items such as "In the past 4 weeks, how often did you feel nervous?" and "In the past 4 weeks, how often did you feel hopeless?".²¹ Participants responded on a five-point scale ranging from 1 = "none of the time" to 5 = "all of the time". Responses were summed to create a total score and categorized as low (scores of 10–15), moderate,^{16–21} high,^{22–29} or very high distress (30–50).

2.3 | Data analysis

Proportions of participants in each K10 severity category and each of the three bowel cancer screening statuses were calculated and graphed. Odds ratios (OR) and 95% confidence intervals (CI) were calculated for linear and quadratic effects of K10 categories on bowel cancer screening status using logistic regressions analyses—including polynomial logistic regression to test the quadratic effect. Firstly, we examined having ever tested for bowel cancer (i.e., tested for bowel cancer in the last 2 years + tested for bowel cancer but not in the last 2 years) versus never tested for bowel cancer, and secondly, we examined having tested for bowel cancer in the past 2 years or not (i.e., tested for bowel cancer, but not in the last 2 years + never tested for bowel cancer). Analyses were completed using IBM SPSS Statistics 21.

2.4 | Results

The majority of K10 scores fell in the low distress category (71.4%) with 16.5% in the moderate distress category, 7.9% in high, and 4.2% very high. Of those surveyed, 32.4% reported having been tested for bowel cancer in the previous 2 years, 22.3% more than 2 years ago, and 45.3% reported never having been tested for bowel cancer.

Logistic regression results showed the linear effect was not significant (OR = 1.39, CI = 0.98, 1.97), however, the quadratic effect was significant (OR = 0.90, CI = 0.83, 0.97) of psychological distress category on whether someone had ever tested for bowel cancer. Figure 1 shows that rates of ever screening were relatively similar between those in low to high distress categories (ranging from 55.9% to 52.7%), but there was a substantial decrease to 38.3% in the very high category. There was a significant linear effect of psychological distress category on having been tested for bowel cancer in the past 2 years, with screening rates decreasing gradually from 33.4% to 22.5% as psychological distress increases from low to very high (OR = 0.88, CI = 0.82, 0.96). There was no significant quadratic effect (OR = 0.94, CI = 0.86, 1.03).

3 | STUDY TWO: 2021 ONLINE SURVEY

3.1 | Methods

3.1.1 | Participants and procedure

Eligible participants included adults residing in Australia between the ages of 50–74 years (i.e., eligible participants of the NBCSP) who reported having ever received a NBCSP kit. Participants were recruited through paid Facebook advertising and through distribution of the survey link to various local community groups frequented by Australians within the target age range, such as general medical practice waiting rooms, community centres, volunteer organizations, and various workplaces. Invitees were offered the opportunity to win one of three grocery vouchers (valued \$20 to \$50).

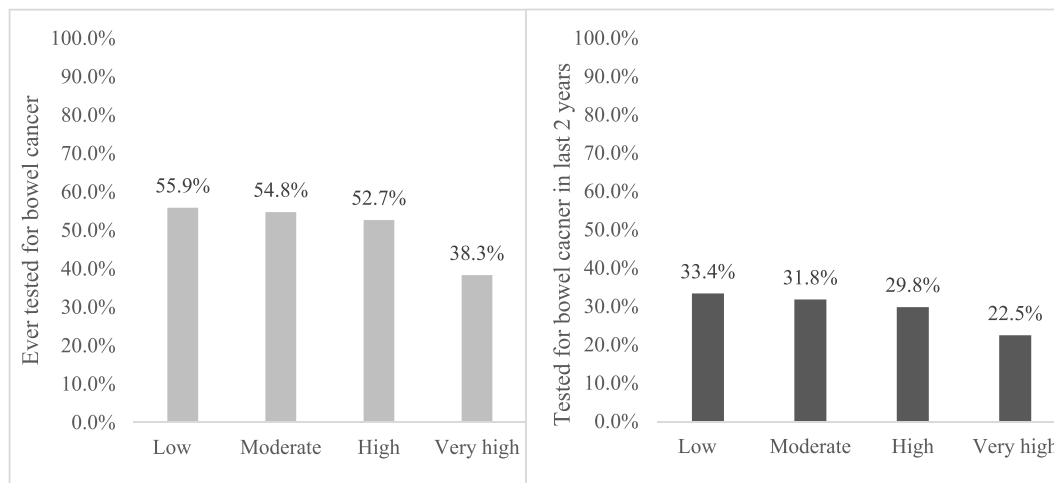


FIGURE 1 Percentage of participants reporting ever testing for bowel cancer, and testing for bowel cancer in the previous two years for each K10 psychological distress group. Figure 1A represents the proportion of the sample who had ever tested for bowel cancer (including those who had done so in the last 2 years) for individuals in each distress severity category. Figure 1B represents the proportion of the sample who had tested for bowel cancer in the previous 2 years for individuals in each distress severity category

Participants completed an anonymous online survey capturing demographic information, bowel cancer screening history, and measures of depression, anxiety, and stress. The survey was delivered via the Qualtrics survey website (Qualtrics, 2017), and the measures relevant to this study took approximately 15 min to complete. Participants provided informed consent, and ethical approval for this research was granted by a university-based Human Research Ethics Committee (ref: H19REA291).

3.1.2 | Participant recruitment

This study formed part of a larger research project whereby one survey link was distributed to potential participants directing them to an online survey with multiple components.^{25,26} Recruitment and attrition for this study are outlined in Supplementary File 1. The final sample consisted of 479 adults between the ages of 50 and 74 years ($M = 61.85$, $SD = 6.91$). A full description of the sample characteristics is provided in Table 2.

3.2 | Measures

Demographic Information. Participants were asked to report their gender, age, income, education level, and residential postcode.

Bowel cancer screening behaviour history. Participants self-reported how recently they had received the NBCSP kit (in months) and whether they returned the completed kit (“yes” or “no”).

Depression Anxiety and Stress Scale. Participants responded to the 21 item DASS-21 instrument designed to measure three subscales capturing variance in the negative emotional states of anxiety, depression, and stress.²² When answering items (e.g., “I found it difficult to relax”) participants were asked to reflect on how they

“generally feel” and indicate how often each item applies to them on a four-point scale ranging from 0 = “not at all” to 3 = “most of the time”. Scores for each subscale were summed and doubled as per scoring instructions.²² Following severity scoring instructions, scores were binned into categories reflecting normal, mild, moderate, severe, and extremely severe.²⁷ Due to low cell size in the “extremely severe” category for anxiety, depression, and stress ($n = 12, 12, 2$, respectively), these were combined with the “severe” category. Within the current sample, the subscales of anxiety, stress, and depression demonstrated acceptable to excellent internal consistency, as indicated by Cronbach’s $\alpha = 0.75, 0.86$ and 0.92 , respectively.

3.3 | Data analysis

Analyses were completed using IBM SPSS Statistics 21.²⁸ The proportion of participants who had returned their most recent FOBT kit was calculated and graphed for each severity category (normal, mild, moderate, and severe/extremely severe) of anxiety, stress, and depression. Odds ratios (OR), and corresponding 95% CIs, of the linear and quadratic effects of anxiety, stress, and depression category membership on bowel cancer screening participation were calculated using logistic regression analyses. Specifically, polynomial logistic regression was used to test the quadratic effect of DASS severity levels on the likelihood of kit return.

3.4 | Results

Over two thirds of participants (67.2%) completed screening by returning their kit. DASS scores indicated that most participants fell into the ‘normal’ category for anxiety (70.2%), with remaining anxiety levels categorised as mild (7.7%), moderate (14.6%), and severe/

TABLE 2 Characteristics of study two sample—online survey (N = 479)

	n ^a	%
Last received kit		
Less than 1 month	23	4.5%
1–3 months	54	10.7%
3–6 months	75	14.8%
6–12 months	85	16.8%
1–2 years	145	28.6%
Over 2 years	97	19.1%
Sex		
Male	185	38.7%
Female	293	61.3%
Relationship		
Married/de facto	325	68.0%
In a relationship (that is not married/de facto)	8	1.7%
Single	53	11.1%
Divorced	57	11.9%
Widowed	27	5.6%
Rather not say	8	1.7%
Remoteness		
Major cities	321	67.4%
Inner regional	107	22.5%
Other	48	10.0%
Area-level SES		
Quintile 1 (lowest)	49	10.3%
Quintile 2	59	12.4%
Quintile 3	101	21.2%
Quintile 4	147	30.9%
Quintile 5 (highest)	120	25.2%
Country of birth		
Australia	352	73.6%
United Kingdom	67	14.0%
New Zealand	17	3.5%
Other	42	9.5%
Highest level of education		
University degree	206	43.0%
TAFE/Apprenticeship	100	20.9%
Year 12	41	8.6%
Year 11	12	2.5%
Year 10 or below	64	12.8%

^aN (%) unless otherwise stated. Total N does not equal 479 where data were missing. Percentage calculated excluding missing data.

extremely severe (7.5%). For stress, the percentage of people in each category were: normal (83.6%), mild (7.9%), moderate (6.1%), and severe/extremely severe (2.4%). For depression, the percentage of people in each category were: normal (71.4%), mild (9.5%), moderate (13.4%), and severe/extremely severe (5.7%). As shown in Figure 2 the percentage of participants who reported returning their kit tended to be lowest for those experiencing severe/extremely severe anxiety, stress, or depression.

There was a significant linear effect of depression on screening kit return, such that those with lower levels of depression were more likely to return their kit (OR = 0.79, CI = 0.64, 0.96). There were no significant linear effects of anxiety or stress on kit return (OR = 0.64, CI = 0.38, 1.07; OR = 0.51, CI = 0.20, 1.29, respectively). There was a significant quadratic effect of anxiety on whether someone had returned their screening kit, such that those with mild and moderate anxiety were more likely to return their kits than those with normal or severe/extremely severe anxiety (OR = 0.44, CI = 0.25, 0.79). There were no significant quadratic effects of stress or depression (OR = 0.89, CI = 0.39, 2.05; OR = 0.90, CI = 0.51, 1.56, respectively).

4 | DISCUSSION

The aim of this research was to examine the relationship between psychological distress and participation in bowel cancer screening using data from two different samples. Combined findings from the current studies suggest that extreme levels of psychological distress, depression and anxiety are associated with a lower probability of participation in bowel cancer screening. This finding helps to clarify prior literature which suggested a complex relationship between distress and bowel cancer screening.^{16,17}

The current findings suggest that moderately heightened psychological distress, particularly anxiety, may facilitate screening behaviour to a certain point—after which, it may act as a barrier to screening. Potentially, people who tend to be low in anxiety or distress may generally be less concerned about their risk of developing bowel cancer and therefore, less motivated to participate in bowel cancer screening.²⁹ Whereas, those with moderate levels of anxiety and psychological distress may experience higher levels of fear or worry about their health, which can be somewhat motivating.³⁰ Recent studies suggest that fear or worry about having cancer can both motivate and deter bowel cancer screening participation in different people,³¹ which fits with the non-linear result from the present study. For example, fear of missing a cancer diagnosis has been shown to facilitate participation in bowel cancer screening,⁵ particularly among regular screeners.³² However, as irregular screeners or non-screeners often report, fear of a cancer diagnosis is a deterrent of screening.^{6,32} The current findings may reflect this tendency for increasing concern to motivate screening to a point,³³ beyond which severe distress or concern leads individuals to avoid screening due to the potential negative consequences. Additionally, extreme or disordered levels of anxiety and distress may exacerbate other emotional or logistic barriers that prevent screening participation.

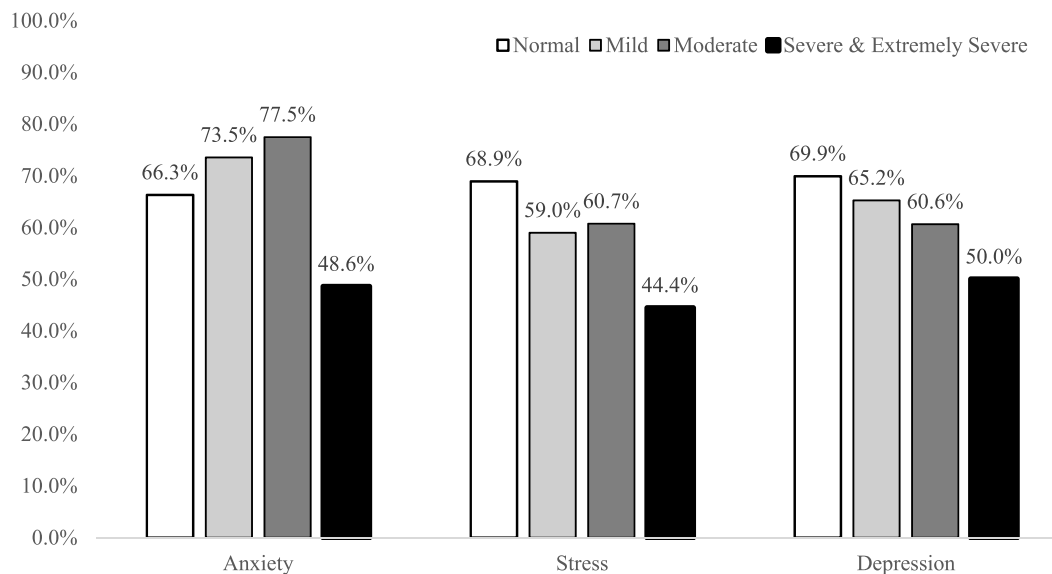


FIGURE 2 Percentage of participants reporting returning their screening test kit for each anxiety, stress, and depression severity level

The current findings also suggest a linear effect for depression whereby people with higher levels of depression were less likely to participate in the NBCSP. The negative effect of depression on health behaviours is well-established as it is thought to reflect challenges with motivation, self-efficacy, and action that coincide with low mood.¹² Significant planning and action are required to read instructions, take the two stool samples, store the samples, and return post them according to particular instructions. Additionally, depression may negatively affect valuing the importance of looking after yourself through screening.³⁴ Future research should investigate the role of these mechanisms in producing low screening participation among those with higher levels of depression.

Stressful life events have often been reported as reasons for delaying or neglecting bowel cancer screening for many people.⁵ However, in the current study, despite the large observed difference between the stress categories of normal and severe/extremely severe (24.5% decline in participation), no significant effect of stress was found. This may be due to the low number of people in the severe/extremely severe stress category ($n = 9$). For comparison, the observed decline of screening participation between normal and severe/extremely severe for anxiety was 17.7% ($n = 35$ for severe/extremely severe category), and 19.9% for depression ($n = 24$ for severe/extremely severe category). This highlights the need for further research on the relationship between stress levels and screening participation to explore whether there is an effect, and if so, the nature of the effect (i.e., linear or quadratic).

5 | CLINICAL IMPLICATIONS

People with mental health disorders are at greater risk of cancer and have a worse prognosis, including higher mortality rates than the general population.³⁵ Poor mental health is also associated with poorer health behaviours such as alcohol use, poor diet, tobacco use,

and obesity³⁶; all associated with increased risk of bowel cancer⁴ highlighting the elevated importance of screening among this population.

Therefore, the current findings have important implications for clinical practice. For example, for mental health and primary care patients with depression may require extra support (i.e., prompting, motivation, and facilitation) to screen for bowel cancer. Health professionals involved in the treatment of people with severe distress or anxiety disorders should be aware of the reduced likelihood that they will be adequately screened for bowel cancer—and potentially other cancers too.³⁵

Communication between primary care and mental health providers is a key area where interventions to improve cancer screening rates among people with mental illness can be implemented.³⁷ For example, a recent pilot study has shown that patient navigation (letter and phone call from a patient navigator to help patients overcome individual barriers to bowel screening) is a promising intervention to increase cancer screening among patients with mental illness.³⁸ Unfortunately, a recent review has shown that there is a lack of randomised control trials of interventions among these populations.³⁹ Efforts to develop and evaluate effective interventions for this group are therefore, vital.^{39,40}

6 | STUDY LIMITATIONS

The current studies include limitations. The NHS data screening outcome included all forms of bowel cancer screening (i.e., more than just NBCSP participation) and only global levels of psychological distress was measured (i.e., the K-10). Further, the NBCSP was not fully in operation when the data were collected (2014/15), so not all participants would have received a kit within the last 2 years. The second study may have been prone to a self-selection bias, and thus, be less generalisable. The self-reported responses are limited by

biases such as social-desirability and memory decay. Further, it is important to note that causality cannot be inferred from the current results. Poor health behaviours such as non-participation in screening could arguably cause someone to feel a certain degree of anxiety. However, longitudinal research confirms that disordered mental health predicts poorer health behaviours, such as substance use, unprotected sex, poor diet and insufficient or excessive sleep.³⁶ In addition, the relationships between distress and screening may reflect general levels of wellbeing, as well as more acute fluctuations for those experiencing severe symptoms. Therefore, further research might profit from investigating the role of state-based mental health.

7 | CONCLUSION

Overall, evidence from a large randomly selected representative sample as well as novel survey data both suggest that extreme levels of psychological distress are associated with lower bowel cancer screening participation rates. This consistent finding in both studies demonstrates generalisability and replicates findings across data sets. Results suggest that sub-clinical increases in anxiety tend to be associated with small increases in the likelihood of bowel cancer screening participation. Whereas those with severe or disordered levels of distress or anxiety may be less likely to take part. Severely distressed individuals may be experiencing other co-morbidities and disorders that impede their ability or capacity to participate in bowel cancer screening making them a vulnerable group and an important target for intervention efforts.³⁹ Improvement of participation in bowel cancer screening by those experiencing extreme levels of distress can save lives through early cancer detection in this vulnerable group.

AUTHOR CONTRIBUTIONS

Conception and design: BG, LM, MI, CA, TC. Data collection: CA, TC. Analysis and interpretation: BG, LA, LM, MI. Drafting or revising manuscript: BG, LA, LM, MI, TC, CA.

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CONFLICT OF INTEREST

The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

ETHICS STATEMENT

These studies were approved by the Human Research Ethics committee of the University of Southern Queensland. Approval numbers: H19REA291 and H20REA282.

PARTICIPANT CONSENT STATEMENT

Participants were informed about the survey and their involvement, however, participation in the NHS is compulsory under Census and Statistics Act 1905.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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