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Colorectal Cancer Screening and Perceived Disgust: The Importance of the "Ick" Factor in Faecal Occult Blood Test Uptake

Abstract

Background: Colorectal cancer is a major cause of cancer deaths worldwide. Screening is key to early detection but uptake of national programmes is poor, especially amongst those from lower socio-economic backgrounds. Decisions not to take up screening may be based more on emotional rather than rational evaluations. We aimed to examine the importance of perceived disgust (the 'ICK' factor) in determining colorectal cancer screening uptake, in a large, randomised controlled trial.

Methods: This paper reports secondary analysis of a randomised controlled trial of a simple, questionnaire-based Anticipated Regret (AR) intervention, which was delivered alongside existing pre-notification letters. 60,000 adults aged 50-74 who were participant in the Scottish National Screening programme were randomised to one of 3 treatment arms: 1) no questionnaire (control), 2) Health Locus of Control (HLOC) questionnaire or 3) AR questionnaire. Primary outcome was Faecal Occult Blood Test kit return (FOBT uptake). 13,645 people completed questionnaires of secondary outcomes including intention to return test kit and a new self-report measure of perceived disgust (ICK-C).

Results: Intentions, ICK and AR were all predictors of FOBT uptake; however, for people who expressed strong intentions to return their FOBT kit, only ICK differentiated kit returners from non-returners, with non-returners reporting higher disgust (mean difference=0.51; 95% CI for difference (0.37, 0.64), Cohen's d=0.34). The 4-item ICK-C showed excellent internal reliability and predictive validity with regard to an objective measure i.e., FOBT uptake.

Conclusions: The findings show that perceived disgust is an important emotional psychological construct in determining uptake of colorectal cancer screening. We also demonstrated that a simple 4-item scale (the 'ICK-C), developed to be used in research on colorectal cancer screening, has excellent psychometric properties.

Keywords: Colorectal cancer; Screening; Faecal occult blood test; Disgust the 'ICK' factor

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Introduction

Colorectal cancer is a major cause of cancer deaths worldwide. Current screening tests are effective at detecting cancers at an early stage, resulting in earlier intervention and significantly reduced mortality [1]. As a result, many western countries have introduced national programmes of colorectal cancer

screening; however, uptake remains relatively poor with overall participation rarely exceeding 60% [2]. The national screening programme in Scotland invites all adults aged 50-74 to complete a guaiac faecal occult blood test (FOBT) every 2 years. This home-based test requires individuals to take their own faecal samples on 3 separate occasions within a 10-day period, and post the completed kit back to the screening centre for testing. Overall

uptake in this programme during the period November 2009 to October 2011 was around 56% [3].

Decisions to engage in health-related behaviours are not just based on rational evaluation of evidence, but are also influenced by emotional beliefs and attitudes ("gut feelings"), including negative feelings such as regret and disgust [4,5]. Regret is experienced when we reflect that an outcome may have been better had we previously taken a different action. We can also anticipate regret and consequently change our behaviour in order to avoid experiencing this negative emotion. Anticipated regret (AR) has relevance in cancer screening, where not being screened may result in a poorer outcome if there is a subsequent diagnosis (e.g., a more advanced and perhaps untreatable cancer), leading to marked regret. AR has been shown to significantly predict behaviour over and above intentions to carry out an action [6] including increasing uptake of cervical cancer screening [7].

Disgust is a negative reaction to noxious stimuli which is universally recognisable across cultures; it is believed to have an adaptive function in protecting against harmful agents of disease or contamination [8]. Disgust has relevance in the health arena as it can lead to avoidance of protective, but nonetheless potentially disgusting, health behaviours, including colorectal cancer screening. For instance, Jones et al. [9] found that major barriers to FOBT screening included not wanting to handle stools, and not wanting to keep stools on a card in the house. A qualitative study of patients invited to participate in the National Health Service screening programme in England confirmed that sampling and storing faeces in the home is a major taboo [10]. Hence, many patients may be missing out on the benefits of colorectal cancer screening because they are put off by their perception that completing the simple screening test kit will be a disgusting thing to do. However, the actual experience of colorectal cancer screening is often found to be less unpleasant than anticipated [11], suggesting that, for those who take part, perceived disgust may have less influence on the decision to participate in future.

Despite the obvious salience of disgust to colorectal cancer screening, only a relatively small number of studies have examined the effect of disgust on colorectal cancer screening uptake. One early study showed that completing an FOBT test kit was considered more disgusting than having a colonoscopy and that self-reported disgust was higher in those failing to participate in screening for colorectal cancer [12]. A recent review by Reynolds et al. [13] found only eight, small-scale, mostly qualitative, cross-sectional studies examining disgust and uptake of colorectal cancer screening. Nonetheless they reported that anticipated disgust was a key barrier to participation in colorectal cancer screening in particular with regard to FOBT test completion. The authors concluded that: "the careful study of disgust may extend our understanding of avoidance in the CRC (colorectal cancer) trajectory" and also highlighted there was a lack of suitable measurement tools designed to identify triggers of disgust. An experimental study aimed to manipulate state disgust and examined its interaction with trait disgust as predictors of colorectal cancer decision-making. Reynolds et al. [14] found that disgust was associated with both immediate and anticipated avoidance behaviours and concluded that: "Designs that assess trait and state disgust in people making real-life decisions about CRC screening and treatment could provide important clinical insights in an area where avoidance is common but in which there has been little research to date." The main aim of the current research was to test a simple, questionnaire-based, AR manipulation in a large sample of the general public invited to take part in colorectal cancer screening. The main results are reported elsewhere [15]. In brief, there was no 'analysis as allocated' ('Intention-to-Treat') effect on FOBT uptake of randomisation to treatment either overall or when broken down by age band, gender or Scottish Index of Multiple Deprivation (SIMD) quintile. Additional aims were to examine the influence of secondary outcomes including emotional measures which may be associated with FOBT uptake. As expected, people with higher self-reported AR and lower perceived disgust (ICK) were more likely to return their kit, and ICK also had a direct effect on FOBT uptake over and above any indirect via intentions [15]. In order to measure ICK we employed a 4-item measure of perceived disgust (the ICK-C) developed from previous research measuring disgust in organ donation [4,16] and barriers to colorectal cancer screening [9,17]. The aim of the current paper is to fully explore and present a secondary analysis of the interactions between AR, disgust, intention strength and avoidance behaviour in colorectal cancer screening in this large population sample. We also report the psychometric properties of the ICK-C and demonstrate its predictive validity with respect to FOBT uptake.

Methods

This was a single-centre trial based at the Scottish Bowel Screening Centre in Dundee. Full details of methods for this randomised controlled trial are reported in the protocol paper [18] and the main results paper [15]. The study is registered with current controlled trials: www.controlled-trials.com Number: ISRCTN74986452.

Participants

Following the method of Libby et al. [19] a large, nationally representative sample of the Scottish general public were sampled via post. Participants were all adults aged 50–74 years, who were participant in the screening programme, and who were due to be invited for screening within the study recruitment period (April to June 2013). As this was a questionnaire-based survey, ethnicity of participants was not known. Written informed consent was not sought from participants, because this was not feasible in the control arm, thus seeking informed consent from those returning questionnaires would have confounded the results. Full UK NHS IRAS ethical approval was obtained for this approach (Tayside NHS Board, East of Scotland Research Ethics Committee; REC ref. no. 12/ES/0092).

All patients currently included in the Scottish Bowel Screening Programme were eligible for this study and there were no exclusion criteria for participation.

Measures

Faecal Occult Blood Test (FOBT) uptake: Primary outcome was return of a used FOBT test kit to the central laboratory at the Scottish Bowel Screening Centre, within 6 months of the kit being sent out (FOBT uptake).

Secondary outcomes: All secondary outcomes on the two questionnaires were measured using simple 1-7 Likert-type scales from 'strongly disagree' to 'strongly agree', and subscales were calculated as means of available items. Two items measured intention to return the FOBT kit ("I will definitely complete and return my test kit" and "I strongly intend to complete and return my test kit") (alpha=0.70). AR was measured by two items placed as the first question of the survey ("If I did not complete and return my test kit, I would later feel regret") and immediately preceding the final intention question ("If I did not complete and return my test kit, I would later wish I had"), following Sandberg and Conner [7] (alpha=0.64). Perceived disgust (ICK) was measured using 2-items derived from the ICK-factor scale used in organ donation [4,16] (i.e., 'The idea of completing my test kit is somewhat disgusting' and 'Completing my test kit will make me feel uncomfortable'), and two items derived from barriers to FOBT completion (i.e., 'I don't like the idea of keeping my stool samples on a card in the house' [9] and 'Completing my test kit will be an unpleasant task' [17]. Perceived benefit (PB) of FOBT screening was measured using a modified version of the perceived benefit scale (2-items, alpha=0.52) from O'Carroll et al. [16] (i.e., 'I am likely to benefit if I complete and return my test kit' and 'I think that bowel screening can help save lives'). We followed guidelines of the Plain English Campaign (www. plainenglish.co.uk) in designing the layout and wording of the questionnaire items, in order to make it as understandable and readable as possible. The questionnaire was pilot tested with a convenience sample of 9 adults aged 50 or over to verify ease of understanding and completion. In addition, the existing 18-items from the well-used and well-validated Health Locus of Control (HLOC) scale [20] were included in both the HLOC and AR guestionnaire, however, as none of the HLOC subscales were related to FOBT uptake in the main analysis, they are not further considered in the current paper.

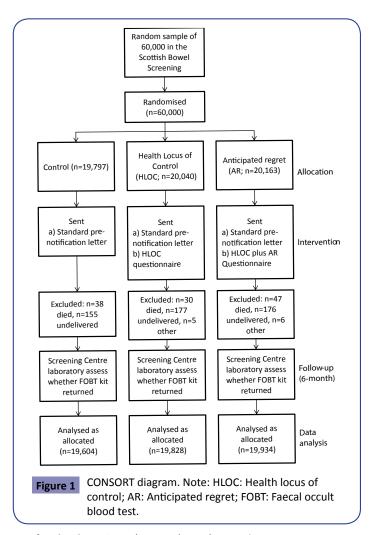
Procedure

This study comprised a simple 3-arm randomized controlled trial (RCT): (1) no questionnaire control (2) HLOC questionnaire control and (3) AR questionnaire. The CONSORT diagram is shown in **Figure 1**. All participants in the Scottish Bowel Screening programme are sent a standard pre-notification letter 2 weeks before being sent a FOBT by post, which they are required to complete at home and then return to the laboratory at the Bowel Screening Centre for analysis. Our questionnaires were included along with the pre-notification letter.

Control group: Participants randomized to the Control group were sent the standard pre-notification letter, as current practice.

HLOC group: Participants randomized to the HLOC intervention were sent the pre-notification letter plus the HLOC scale. HLOC participants were also completed the ICK and PB items as well as intention to return their kit.

AR Intervention: Participants randomized to the AR intervention were sent the pre-notification letter and the same HLOC/ICK/PB/intentions questionnaire as the HLOC group plus the 2 additional anticipated regret (AR) questions.



Randomisation: Sampling and randomization were computer-generated by the external IT company which manages the Scottish Bowel Screening Centre IT database, independently of the researchers, using simple randomization to allocate individuals to control, HLOC or AR in a 1:1:1 ratio. The prenotification letters are currently generated and mailed by a not-for-profit, mail-handling company. The questionnaires were added to the letters at the time of mailing, further blinding the researchers to the allocation of the intervention to individuals. A unique identifier was used to record-link the questionnaire data with each individual's subsequent FOBT return.

Statistical analysis

All analysis was carried out in SPSS version 19. Factor analysis using Principle Components and Cronbach's alpha were used to assess the psychometric properties of the ICK-C scale. T-tests were used to assess basic differences between treatment groups and logistic regression was used to assess predictors of FOBT uptake. As the main analysis showed that intention both acted as a mediator of the secondary outcome variables on FOBT uptake, and also that intention strength was a moderator of AR, analyses were additionally carried out split by intention strength (i.e., less than strong intenders M<=6.5 versus strong intenders M>6.5; this cut-off was chosen as the median intentions scores was 7, representing 'strongly agree' on both intention items).

Our extremely large sample size means that reliance should not be placed on significant p-values, as "in very large samples, p-values go quickly to zero, and solely relying on p-values can lead the researcher to claim support for results of no practical significance" [21]. Appropriate effect sizes (Cohen's d and odds ratios) and 95% confidence intervals (CI) are therefore reported for all analyses, as these provide a range for the magnitude of the observed effect.

Results

Participants

60,000 participants were randomized to the Control (n=19,797), HLOC (n=20,040) and AR (n=20,163) treatment arms (Figure 1). A number (n=634) of participants were excluded from the analysis as addresses were not in Scotland (n=13), participants declined consent (n=7), withdrew from the screening programme (n=4) or did not receive the pre-notification letter (n=115 died, n=104 transferred out (of Scotland), n=391 undelivered (e.g., 'returned to sender')). There were no differences in exclusions by treatment group. Table 1 shows demographic data for the included participants by treatment group; there were no differences between groups indicating the randomization was successful.

Analysis as Allocated ('Intention to Treat (ITT)') Overall, 57.2% of people returned a FOBT kit. There were no differences between the three treatment groups, either overall (i.e., Control: 57.3%, HLOC: 56.9%, AR: 57.4%) or when broken down by gender, age band or SIMD quintiles O'Carroll et al. [5] indicating that the intervention did not have an effect on FOBT uptake in the ITT analysis.

Questionnaire returns

Overall 13,645 (34.2%) people filled in and returned questionnaires between May 2013 and February 2014. There was only a small amount of missing data missing for each questionnaire item (ranging from 0.3% to 1.6%). For individuals returning questionnaires, means for all secondary outcome measures which had fewer than 50% of items completed (N=161) were imputed, using the fully conditional model in SPSS, with age, gender, SIMD quintile, previous kits returned, previous failures to return kit and the remaining secondary outcome measures as predictor variables. Single iteration was performed as the amount of missing data was very small (0.3%). Imputed means were constrained to be between 1 and 7. The number of individual missing items on the ICK scale was also very small (ranging from 0.4% to 1.2%); missing items were replaced by item means in the Principle Components Analysis.

Factor analysis

Principle Components analysis was used to examine the psychometric properties of the 4-item ICK-C scale: a single factor explained 71.1% of the variance in perceived disgust, with high loadings for all items (0.81 to 0.87) and very high internal reliability (Cronbach's alpha=0.87) (Table 2). The excellent psychometric properties were observed across all subgroups, including at strong

Table 1 Demographics by treatment group (n=59,366).

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Note: ^aValid n for SIMD quintile is 59,232 as some SIMD codes were unobtainable.

and less than strong intentions, whether or not the participant returned their FOBT kit (Table 2) and age band, gender and SIMD quintiles (data available from the authors).

Psychological measures and FOBT uptake

Table 3 shows the mean scores of intentions, ICK, AR and PB for those returning questionnaires by FOBT uptake split by those with less than strong and strong intentions. Results for individual ICK items are also shown. It can be seen that overall, those who returned their FOBT kit had significantly lower ICK scores than those not completing their kit and this held for both those with less that strong and strong intentions. In contrast AR and PB

differentiated FOBT uptake amongst those with less than strong intentions but there was no effect for those with strong intentions. Thus ICK was the only psychological measure which differentiated kit return amongst those who held strong intentions to return their kit (Table 3). The ICK items which showed the greatest differences between kit returners and non-returners were 'I don't like the idea of keeping my stool samples on a card in the house' and 'Completing my test kit will make me feel uncomfortable'.

ICK and kit return history

As expected, ICK scores were related to kit return history with those who had previously returned one or more kits having lower scores (i.e., mean=2.95 (standard deviation (SD)=1.4) than those with zero previous returns (mean=3.68 (SD=1.6), 95% CI for difference (0.66, 0.79)) and those with one or more previous failures having higher ICK scores (i.e., mean=3.55 (SD=1.6)

than those with zero failures (mean=2.96 (SD=1.4), 95% CI for difference (0.53, 0.65)).

Logistic regression

Table 4 shows the results of a logistic regression analysis of the secondary outcome measures as predictors of FOBT uptake, adjusted for gender, age band, SIMD quintile and kit return history (i.e., number of previous kits returned and number of previous failures to return kit), as these variables were all related to FOBT uptake in the main analysis [15]. Results are shown for the whole sample (excluding the AR measure) and the AR group only (with AR included) and are also split by intention strength. For the whole sample, both ICK and PB were significant predictors of FOBT uptake, over and above the demographic and kit return history variables, both overall and for those with less than strong intentions. However, only ICK (not PB) predicted FOBT uptake

Table 2 Principle Components Analysis of the ICK-C items.

Factor loadings	Whole sample	Less than strong intentions		Strong intentions		
		Did not return kit	Returned kit	Did not return kit	Returned kit	
n	13645	768	484	3687	8706	
The idea of completing my test kit is somewhat disgusting	0.86	0.87	0.87	0.83	0.85	
Completing my test kit will be an unpleasant task	0.87	0.88	0.87	0.84	0.86	
don't like the idea of keeping my stool samples on a card in the house	0.83	0.83	0.82	0.81	0.83	
Completing my test kit will make me feel uncomfortable	0.81	0.84	0.81	0.84	0.79	
Variance explained	71.1%	72.9%	70.7%	68.9%	69.4%	
Eigenvalue	2.8	2.9	2.8	2.8	2.8	
Cronbach's alpha	0.87	0.88	0.86	0.86	0.85	

Note: The Principle Components Analysis produced very similar results when broken down by age band, gender and/or SIMD quintile and/or combinations of these variables (data available from the authors).

Table 3 Mean (SD) scores of secondary outcome measures by FOBT uptake and intention strength.

Whole sample					Less than strong intenders			Strong intenders		
FOBT uptake:	All	Υ	N	Mean difference (95% CI) Cohen's d	Y	N	Mean difference (95% CI)	Υ	N	Mean difference (95% CI)
n	6692	6613	579		2093	380		4020	199	
AR	6.19 (1.0)	6.25 (0.9)	5.57 (1.5)	0.68 (0.59, 0.76) d=0.67	5.66 (1.0)	5.07 (1.5)	0.59 (0.48, 0.71) d=0.55	6.56 (0.8)	6.54 (0.7)	0.02 (-0.08, 0.13) d=0.03
n	13645	12393	1252		3687	768		8706	484	
Intentions	6.65 (0.7)	6.71 (0.6)	6.00 (1.4)	0.72 (0.68, 0.76) d=1.00	6.04 (0.7)	5.37 (1.5)	0.68 (0.61, 0.74) d=0.76	7.00 (0.0)	7.00 (0.0)	0.00 (-0.001, 0.00) d=0.00
РВ	6.47 (0.7)	6.53 (0.7)	6.22 (0.9)	0.31 (0.27, 0.35) d=0.45	6.11 (0.7)	5.90 (1.0))	0.21 (0.15, 0.27) d=0.27	6.71 (0.5)	6.72 (0.6)	0.01 (-0.04, 0.06) d=0.02
ICK	3.08 (1.5)	3.00 (1.5)	3.78 (1.6)	0.79 (0.70,0.87) d=0.53	3.43 (1.4)	4.07 (1.5)	0.65 (0.54, 0.75) d=0.46	2.82 (1.5)	3.36 (1.6)	0.51 (0.37, 0.64) d=0.34
Disgusting	3.03 (1.9)	2.97 (1.8)	3.68 (1.9)	0.71 (0.60, 0.82) d=0.38	3.41 (1.7)	3.99 (1.8)	0.57 (0.44, 0.71) d=0.33	2.78 (1.9)	3.19 (2.0)	0.41 (0.24, 0.58) d=0.22
Unpleasant	3.55 (1.9)	3.49 (1.9)	4.18 (1.9)	0.69 (0.58, 0.80) d=0.37	3.84 (1.7)	4.41 (1.7)	0.57 (0.44, 0.70) d=0.33	3.34 (1.9)	3.80 (2.0)	0.47 (0.29, 0.64) d=0.24
Stools on card	3.09 (1.85)	3.01 (1.7)	3.89 (1.9)	0.88 (0.79, 0.98) d=0.52	3.48 (1.6)	4.21 (1.7)	0.73 (0.61, 0.86) d=0.45	2.81 (1.7)	3.38 (1.9)	0.57 (0.41, 0.72) d=0.34
Uncomfortable	2.53 (3.41)	2.5 (1.6)	3.41 (1.8)	0.88 (0.78,0.97) d=0.54	2.97 (1.5)	3.71 (1.7)	0.74 (0.61, 0.88) d=0.47	2.34 (1.6)	2.92 (1.8)	0.58 (0.43, 0.73) d=0.36

Note: All differences have been calculated as higher score minus lower score.

Table 4 Logistic regression of FOBT uptake by intention strength adjusted for demographics and kit return history.

	^a Adjusted odds ratio (95% CI)							
	Whole sample	Less than strong intentions	Strong intentions					
HLOC & AR groups	HLOC & AR groups (n=13645)							
ICK	0.86 (0.82, 0.89)	0.88 (0.83, 0.94)	0.88 (0.82, 0.94)					
PB	1.31 (1.21, 1.42)	1.22 (1.10, 1.36)	0.90 (0.74, 1.10)					
AR group (n=6692)							
ICK	0.88 (0.82, 0.94)	0.95 (0.86, 1.04)	0.84 (0.76, 0.93)					
PB	1.07 (0.93, 1.24)	0.98 (0.83, 1.17)	0.91 (0.66, 1.25)					
AR	1.24 (1.13, 1.42)	1.27 (1.13, 1.42)	0.96 (0.78, 1.18)					

Note: Adjusted for the secondary outcome measures, plus age band, gender SIMD quintile, number of previous kits returned and number of previous failures to return kit.

amongst those with strong intentions. For the AR group, ICK, PB and AR were all significant predictors overall, but again only ICK acted as a predictor of FOBT uptake for those with strong intentions. AR was the only significant predictor of FOBT uptake in those with less than strong intentions, indicating that neither ICK not PB explained any additional variance in FOBT uptake over and above AR in this group. The results suggest that AR may have attenuated the negative effects of ICK in those randomized to the AR intervention.

Discussion

In this paper we have demonstrated that perceived disgust is an important factor in determining failure to complete an FOBT kit, even amongst those with high intentions. Our brief (4-item), simple to use measure of perceived disgust (the ICK-C) targeted at colorectal cancer screening resulted in a single factor with excellent reliability and good psychometric properties. Further, this factor had good predictive validity with regard to FOBT uptake, over and above other psychological constructs including AR and PB. The fact that, even amongst those most predisposed to return their kit (strong intenders), higher perceived disgust was evident in those who failed to return the kit indicates that the anticipated unpleasantness of the task may be a key barrier to carrying through intentions to complete a screening test. The current FOBT kit has to be completed on 3 separate occasions, in the meantime stool samples are held on a card in a house, and emotions such as disgust and embarrassment associated with this act may lead to even the most determined being put off in completing it. Indeed the item 'I don't like the idea of keeping my stool samples on a card in the house' was more strongly related to failure to return the kit than other items including 'Completing my test kit will be an unpleasant task'. Replacing the FOBT kit with a single-use kit (e.g., the Faecal Immunochemical test 'FIT') has been shown to increase uptake [22], possibly because it is easier to complete but also as it may reduce patients' experience of negative associations including disgust [23]. As the single-use FIT test will soon be implemented in Scotland, reasons for any increases in uptake need to be clarified in further research.

Lower ICK scores were also evident in those who had previously completed and returned an FOBT kit, which is consistent with the findings of other studies of colorectal cancer screening tests who found that negative feelings such as embarrassment were heightened when viewed in anticipation in comparison

to that reported in hindsight [11]. Thus, persuading potential participants, especially those who are invited for the first time or who have failed to return any previous kit, that the experience of completing the FOBT kit may not turn out to be as disagreeable as they perceive, could also have the potential to improve uptake. One way of achieving this could be via the use of narratives, which present the views of 'real' people regarding completing the test; narrative printed material has been shown to lead to more positive beliefs about screening, including a reduction in disgust, which in turn increased intention to complete a FOBT kit [24]. Our findings add to this research in that we have demonstrated that higher disgust negatively impacts on actual FOBT uptake and not just intention to return a kit.

It should be noted that most people in the current study had relatively low scores of perceived disgust, with mean scores only exceeding the midpoint of the scale (i.e., 4 representing 'neither agree nor disagree', where 5 would be 'slightly agree') for less than strong intenders who did not return their kit. The low disgust scores in this sample are likely to reflect the fact that most of those returning questionnaires also reported strong intentions to return their kit, with the majority actually doing so.

Strengths and Limitations

Strengths of the current study include the large sample size, increasing the generalizability of findings, and the use of an objective outcome measure of behaviour, against which the predictive value of the ICK-C could be evaluated. However, there was a bias towards both questionnaire and kit return meaning data on the secondary outcome measures, including ICK, for those not participating in screening was limited. Questionnaire return was also related to demographic variables including age, gender and SIMD thus this may also represent a biased sample. Further, the ICK-C was not validated against other measures of disgust such as the disgust scale [25] Nonetheless, factor analysis by subgroups (including different age bands, gender and SIMD quintiles) showed similar, excellent psychometric properties, suggesting the ICK-C scale could be appropriately used to assess perceived disgust in all groups invited to take part in colorectal cancer screening.

Conclusion

The findings show that the under-examined psychological construct of perceived disgust (ICK) is an important factor in

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determining FOBT uptake, and further research is warranted. The 4-item ICK-C scale of perceived disgust showed excellent psychometric properties and could be easily used in further research into uptake of colorectal cancer screening.

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