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Public appreciation of lifestyle risk factors for colorectal cancer and awareness of bowel cancer screening: a cross-sectional study

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**PUBLIC APPRECIATION OF LIFESTYLE RISK FACTORS FOR
COLORECTAL CANCER AND AWARENESS OF BOWEL CANCER
SCREENING: A CROSS-SECTIONAL STUDY**

Running title: Public awareness of colorectal cancer risk and screening

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Abstract

Introduction: Prevention of colorectal cancer (CRC) via reduction of lifestyle risk factors, and participation in bowel screening are two ways in which public engagement could lower mortality from colorectal cancer. This study examined public awareness of lifestyle risk factors and bowel screening, with determination of the factors affecting this.

Methods: A representative population sample (n=1969) was surveyed using a study specific postal questionnaire to determine demographics, experience of bowel problems, awareness of lifestyle risk factors, knowledge about the incidence of CRC and potential benefits of screening, as well as personal experience of screening.

Results: The majority of respondents were aged over 50 (74%). 77% had either personal experience or a relative/friend with experience of a bowel problem. Knowledge of dietary advice was better than risks relating to weight and physical activity. Awareness of lifestyle risk factors was significantly worse in those less than 50 years old ($p=0.0004$) and with a lower level of education ($p=0.0021$). Awareness of bowel cancer diagnosis was significantly lower in those less than 50 years old ($p<0.0001$). The most frequent reason for non-completion of a screening kit was that the process was dirty and unpleasant.

Conclusion: Initiatives are required to improve awareness of younger people with regard to lifestyle risk factors for CRC, especially since this group stand to benefit most from risk reduction. Those with a lower educational level also had poor awareness but felt that the NHS should not prescribe exercise and lifestyle change; targeting this group would need to take this into account.

1. Introduction

The burden of bowel disorders is rapidly increasing worldwide and consumes a significant proportion of health care resources. In the UK population, colorectal cancer (CRC) remains the third most common cancer in both men and women [1]. With developments in treatment, mortality has improved over the last 20 years [2]. Despite this, CRC remains the second biggest cancer killer in the UK with over 16,000 deaths each year [2]. Mortality in the UK is worse than that in other European countries [3]. This is partly due to the advanced stage of disease at diagnosis and to delays occurring between symptoms, presentation and treatment.

Primary prevention of CRC can be achieved by targeting modifiable risk factors [4]. Mortality can be further reduced by secondary prevention via screening to enable early diagnosis and excision of adenomas, which may subsequently develop into cancer [4].

The NHS Bowel Cancer Screening Programme (BCSP) was introduced in the UK in 2006 and currently uses faecal occult blood testing every two years between the ages of 60-74 in England and Wales, and between 50-74 in Scotland [5]. The programme is also rolling out screening via flexible sigmoidoscopy at the age of 55 years [5]. The aims of the BCSP are prevention and early diagnosis. A systematic review of studies assessing screening shows that effective screening can reduce mortality from CRC by 16% [6] although this is dependant on uptake.

The success of screening depends on public participation; this in turn depends on public understanding about why screening is important. The national target for BCSP is an uptake rate of 60% [7]. Overall uptake is currently 54% [8], considerably lower than for breast or cervical cancer screening programmes [9,10]. Little is known about public beliefs regarding screening or the experience of those who participate. Knowledge of CRC signs and symptoms

has been shown to affect participation in screening [11]. Awareness of the risk factors for CRC is also an independent predictor for intention to participate in screening [11,12].

Modification of lifestyle risk factors has the potential to significantly reduce CRC risk [13]. A study comparing rates of CRCs across Europe found that 53% of CRCs are potentially avoidable through lifestyle modification [14]. Similarly, the World Cancer Research Fund, which focuses on cancer prevention, estimates that 47% of CRCs in the UK are preventable [15]. Individual ability to reduce risk factors depends on knowledge and understanding; although these do not necessarily equate to behaviour change, they may facilitate it.

A series of campaigns over recent years have aimed to improve public knowledge about cancers. These include a series of campaigns by Public Health England under the 'Be Clear on Cancer' banner, with ongoing campaigns to improve awareness of symptoms and encourage help-seeking and early diagnosis [16]. The National Awareness and Early Diagnosis Initiative (NAEDI) was established in 2008 and is jointly led by Cancer Research UK and the Department of Health [17]. As part of these campaigns, the UK Government launched the National Bowel Cancer Awareness Campaign in January 2012, this targeted lower socioeconomic groups over the age of 55 [18].

Despite these campaigns and the considerable health funding spent on them, public knowledge of lifestyle risks specifically linked to CRC remains unclear.

The aim of this study was to examine public awareness of lifestyle risk factors as well as knowledge and experience regarding bowel screening, with determination of the factors affecting awareness.

2. Material and methods

2.1 Sample

The questionnaire was sent as a postal survey with a charity mailshot from Bowel & Cancer Research (B&CR) charity. 50,000 questionnaires were distributed and were sent to selected postcode areas to achieve a representative sample across England. The postcode areas were: Gloucester GL52, GL53, GL51; Birmingham B15, B17; Exeter EX2, EX3, EX5; Ipswich IP5, IP6, IP10, IP13 and Maidstone ME14, ME15, ME18, ME19. The questionnaire was anonymous and was returned to B&CR in a freepost envelope.

2.2 Questionnaire

A study specific questionnaire was used, including 5 sections and 26 questions in total. Figure 1 shows the study questionnaire. The final 3 questions were included specifically to improve awareness of the work of B&CR charity.

2.3 Statistical analysis

Data analysis was carried out using Statistical Package for the Social Sciences version 23.0 (SPSS Inc., Chicago, USA). Descriptive statistics including median, mean, percentages and odds ratios (OR) with 95% confidence intervals (CI) are reported where appropriate. The unpaired t-test was used to compare means from continuous data and the chi-squared test was used to compare proportions from categorical variables. Missing answers to the lifestyle risk factor questions were classified as incorrect. P-values <0.05 were taken to indicate statistical significance.

3. Results

1969 replies to the questionnaire were received, giving an overall response rate of 4%. All received questionnaires were included in analysis. There was a good overall completion rate of the questions, with 96.4% completed.

Table 1 shows the demographic details of the respondents. The majority of the respondents were female, over 65, educated to degree level and of white ethnicity. Only 7% of the sample had no educational qualifications.

Participants were asked whether they, a family member or friend had ever suffered from a bowel problem; figure 2 shows the percentage with experience of bowel problems. Overall, 77% of respondents had either personal experience or a family member/friend with experience of a bowel problem. 29% had experience of more than one problem. Irritable bowel syndrome was the most frequently experienced condition, with 39% of respondents. 45% of respondents felt that these bowel problems caused problems with day-to-day living. However, only 35% felt that these problems led to feelings of isolation or inability to participate fully socially.

The majority of the respondents had some awareness of lifestyle risk factors with two thirds answering more than half of the questions correctly. Figure 3 shows the percentage of correct/incorrect answers for the lifestyle risk factor questions. Less than 1% of respondents answered all the questions correctly. The median number of correct answers was 4 out of 7 (31.8% of respondents), with a mean of 3.88. There was considerably better awareness of dietary lifestyle factors than those relating to weight and physical activity.

Table 2 shows analysis of the factors determining knowledge of lifestyle risk factors. Awareness of lifestyle risk factors was significantly worse in those less than 50 years old ($p=0.0004$) and with a lower level of education ($p=0.0021$). It was not affected by gender, ethnicity or experience of bowel problems.

Question 15 asked whether the NHS should provide prescriptions for exercise and lifestyle changes. Respondents were evenly divided, with 53% answering yes and 47% answering no. Table 3 shows factors affecting response to this question. Respondents aged less than 35 were significantly more likely to answer yes (OR 2.52) as were those with higher educational level (OR 1.76) and those with experience of bowel problems (OR 1.42). The proportion answering 'yes' to this question decreased with increasing age, 73.4% of those aged 18-34 said yes; 61.2% of those 35-49; 56.4% of those 50-64 and 44.5% aged over 65 answered yes. A similar pattern was seen with educational level, 62.0% of those with a degree answered yes, 51.7% of those with A-levels, 47.4% of those with GCSE level qualifications but only 35.4% of those with no formal educational qualifications answered yes.

The next section of the questionnaire asked about bowel cancer diagnosis and screening. The majority of respondents (62%) were unaware how common CRC is. 45% were unaware that CRC is the second biggest cancer killer in the UK. Similarly, 45% were unaware that it is one of the easiest cancers to cure if caught early. Analysis of the factors affecting awareness of bowel cancer diagnosis, showed that knowledge was significantly lower in those under 50 ($p<0.0001$) and in those educated to degree/A-level qualifications ($p=0.0409$) vs. GCSE/other/no formal qualifications. Awareness of bowel cancer diagnosis was not affected by gender, ethnicity or experience of bowel problems.

Around half (51%) of respondents knew that the screening programme reduces mortality by 16%. 6/10 respondents had either received a screening kit themselves, or had a family member receive one. 91% who had received a kit for themselves had completed it; of those who did not complete the test 26% had valid reasons for non-completion. These included, that

the respondent was outside the age bracket for screening (n=12), had other bowel problems (n=2), an ileostomy (n=2), already had bowel cancer (n=1) or were under surveillance following previous bowel cancer (n=4).

By far the most frequent reason for non-completion in eligible respondents was that the process was dirty and unpleasant. Other reasons for non-completion included concerns over false positive results (n=1), being unconcerned about bowel cancer (n=4), being unwell for another reason (n=4), or simply not getting around to completing the test (n=10).

Respondents who had not completed the test were asked what would have made them complete it. 23 respondents (27% of those answering this question) would complete a blood test, with slightly fewer, 21 (25%) opting for a salivary test. 17% felt they would have completed it if the method had been less distasteful.

The questions in the final section related to B&CR charity. Over half (56%) of respondents knew that B&CR is a national charity funding research into bowel cancer but far fewer (32%) knew that it funds research into all forms of bowel disease. 25% were interested in receiving details of a programme involving members of the public in research.

4. Discussion

The majority of the respondents were female, over 65 and university educated. These groups have previously been found to be more likely to respond to surveys [19], and women and those over 60 also report more willingness to participate in health research [19]. The ethnicity of the sample was not representative of the UK population, because of this it was not possible to assess the impact this has on understanding and knowledge about CRC. Other questionnaires have shown similar inability to sample those in other ethnic groups through this type of study methodology [20]. Ethnicity has been previously shown to affect awareness of symptoms [21], knowledge of screening programmes [22] and attendance for screening [23].

Bowel problems are very common and the findings of this study reflect that, with 77% of respondents having experienced bowel problems in themselves or in a family member/friend. Even this is probably an underestimation as some bowel problems may be common but not discussed, this is particularly true of faecal incontinence [24]. There is general reluctance in the UK population to discuss bowel problems. A study assessing understanding of CRC risk in European countries found that in the UK 84% of people felt that embarrassment about discussing bowel symptoms led to potential delays in seeking help [25]. Our analyses showed that experience of bowel problems did not affect knowledge about CRC or risk factors.

Knowledge about CRC incidence was poor with nearly two thirds of respondents being unaware of how common bowel cancer is. 45% were unaware that CRC is one of the easiest cancers to cure if caught early. Public awareness campaigns have focused on symptom awareness rather than conveying this message but it is crucial the public understands this fact in order to engage with the screening programme. It is possible that there is less public discussion about CRC than for some other cancers. In a study of 1004 people attending outpatient clinics there was significantly better knowledge about breast cancer than CRC [26]. This is not surprising given that studies analysing UK newspapers found coverage of CRC was under-represented relative to the population burden [27,28].

This study used closed direct questions about individual risk factors, as these are better suited to a postal questionnaire. Closed questions have been shown to result in higher levels of knowledge than open questions, as recognition is easier than recall [29]. Using interview techniques, open questioning is possible; with these methods one study of 1637 participants

found that 58% were unable to name any risk factors for CRC [12]. In our study, respondents demonstrated reasonable awareness of general information about lifestyle risks but did not know specific information. For example, 79% knew that eating too much meat increased risk but only 47% knew the advised amount of red meat and only 28% knew the advised amount of processed meat. These findings emphasise the importance of easily memorable messages in health promotion.

Knowledge about dietary risks was better than knowledge about the impact of weight or physical activity. Similar patterns have been identified previously; in the paper about CRC risk awareness in European countries discussed above, 70% were aware of dietary factors, only 30% knew that lack of exercise was a risk factor [25]. A recent poll conducted for the World Cancer Research Fund found that 54% of the UK public did not know about the link between physical inactivity and cancer [30]. Recent health campaigns have targeted both healthy eating and regular exercise and it is possible that campaigns relating to cardiovascular health are improving public awareness of dietary risk.

Age and education affected awareness of lifestyle risk factors and knowledge about CRC, with those under 50 and with lower levels of education having significantly poorer awareness. This is despite the fact that young people could achieve the greatest risk reduction by modifying lifestyle factors. It is possible that health promotion messages are not reaching this group, or that they have less concern about cancer risk. Previous studies of awareness about lifestyle risk have found similar patterns [13,22,31]. We did not specifically collect data about socio-economic group, which has some overlap with educational level; this affects cancer awareness [22,32], screening uptake [33] and behavioural risk [34]. Essentially, those most in need of lifestyle changes are those least likely to be aware of modifications they could make to potentially reduce risk [4].

Question 15 about NHS prescriptions for exercise and lifestyle changes revealed some interesting patterns. 73% of those aged less than 35 answered yes compared with 45% of those aged over 65. There was also an association with educational level, only 35% of those with no formal education answered yes to this question. The reasons for these patterns are likely to be complex and further exploration using qualitative methodology would be interesting. It is possible that younger people want guidance, as they are unsure about ways to modify their lifestyle, as evidenced by their lower level of knowledge. Older people may not want to be told what to do or might feel that risk modification is not worthwhile. Those with no formal education had lowest awareness but the results show that they may be resistant to attempts to prescribe lifestyle change. Exercise-on-prescription schemes have been successfully introduced in parts of the UK but the evidence base for these remains poor [35].

In this sample group, the vast majority of respondents who had received a kit for themselves had completed it. The most frequent reason for non-completion was that the process was dirty and unpleasant; this is in keeping with the findings of previous qualitative studies exploring reasons for reluctance to participate [36,37]. In this study, 26% of those not completing the screening test gave valid reasons for not participating. When assessing completion rates for screening kits, studies and official figures may need to take into account the proportion that do not complete it as they feel they are ineligible.

This study has some limitations. As discussed above, the majority of respondents were female and over 65, and there was poor representation of ethnic groups. The questionnaire failed to engage the interest of some groups, but standard methods of highlighting risk to the public are also likely to fail to reach the same groups. It is not possible to know whether respondents and non-respondents differed systematically. It may be that those who were more interested in CRC responded, however in that case the results are an overestimate of public awareness. A non-validated measurement tool was used to facilitate inclusion of questions specifically

relating to B&CR. The questionnaire relied on the respondents' self-reporting participation in BCSP but previous studies have shown that this is accurate [38].

This questionnaire was sent with a charity mailshot. It was not addressed to individuals and was deliberately sent to locations geographically removed from the charity with the primary intention of raising awareness and enlisting new donors. As the questionnaire was the secondary intention, no specific measures were taken to improve response rate. The average response rate to direct mail for the charity sector in the UK is 1% [39]. Our response rate of 4% may be considered low in comparison to clinical studies, which target a defined population, but for a direct mail marketing campaign, 4% is a reasonable response.

Improving awareness of lifestyle risk can only work in conjunction with other measures including changes to legislation, for example, advertising rules and public health campaigns. These campaigns may use a variety of techniques in order to target different groups and reach a broad population; methods include traditional marketing, use of social and digital media, public relations and special events, printed materials and promotions.

Further exploration of the factors determining awareness about bowel cancer is required to fully understand the patterns seen and qualitative methodology may be useful. Improved awareness does not necessarily lead to behaviour change but the two are linked [40] and targeting understanding of risk has been seen as a relatively gentle way to achieve behaviour change. Educational initiatives need to tackle inequalities in awareness [4] and tailor information delivery to the intended recipients [32]. The process of bowel cancer screening may be a key opportunity to improve awareness of risk factors and bowel cancer knowledge [41].

5. Conclusion

The majority of people have some experience of bowel problems. Educational initiatives are required to improve the awareness of younger people with regard to lifestyle risk factors for CRC, especially since this group stand to benefit most from risk reduction. Those with a lower level of education also had poor awareness of risk factors but felt that the NHS should not prescribe exercise or lifestyle change; targeting this group would need to take this into account.

Conflicts of interest

None

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Table 1
Sample characteristics (N = 1969)

	Number	%
Gender		
Male	597	30.3
Female	1353	68.7
Missing	19	1.0
Age (years)		
18 – 34	130	6.6
35 – 49	373	18.9
50 – 64	657	33.4
>65	800	40.6
Missing	9	0.5
Ethnicity		
White	1916	97.3
Other ethnicity	45	2.3
Missing	8	0.4
Education level		
Degree	839	42.6
A-levels	329	16.7
GCSE	459	23.3
Other	171	8.7
None	129	6.6
Missing	42	2.1

Table 2

Factors determining knowledge of lifestyle risk factors

	Number	Mean score Questions 8-14	p value (two tailed unpaired t test)
Overall	1969	3.881	
Gender			
Male	597	3.956	0.1253
Female	1353	3.846	
Age (years)			
18 – 49	503	3.688	0.0004*
> 50	1457	3.956	
Ethnicity			
White	1916	3.882	0.9747
Other ethnicity	45	3.889	
Education level			
Degree/A-levels	1168	3.979	0.0021*
GCSE/other/none	759	3.771	
Experience of bowel problem			
Experience	1513	3.852	0.1133
No experience	456	3.976	

* = Significant at $p = <0.05$ level**Table 3**

Factors affecting response to Question 15: 'Do you think that the NHS should provide prescriptions for exercise and lifestyle changes as well as for medicines?'

	Yes n (%)	No n (%)	Odds ratio (95% confidence interval)	p value
Overall	1021 (53.3)	894 (46.7)		
Gender				
Male	300 (51.6)	281 (48.4)	0.8991	0.2863
Female	716 (54.3)	603 (45.7)	(0.7395 – 1.0932)	
Age (years)				
18 – 34	91 (73.4)	33 (26.6)	2.5201	<0.0001*
> 35	929 (52.2)	849 (47.8)	(1.6741 - 3.7936)	
Ethnicity				
White	994 (53.2)	873 (46.8)	1.2686	0.4430
Other ethnicity	26 (59.1)	18 (40.9)	(0.6908 - 2.3297)	
Education level				
Degree/A-levels	672 (59.1)	465 (40.9)	1.7610	<0.0001*
GCSE/other/none	334 (45.1)	407 (54.9)	(1.4609 - 2.1228)	
Experience of bowel problem				
Experience	817 (55.3)	660 (44.7)	1.4199	0.0013*
No experience	204 (46.6)	234 (53.4)	(1.1464 - 1.7586)	

* = Significant at $p = <0.05$ level.

Figure 1. Study questionnaire

Figure 2. Percentage of sample with personal/family/friend experience of bowel problems

Figure 3. Percentage sample with correct answers to lifestyle risk factor questions

ACCEPTED MANUSCRIPT

PLEASE DON'T DELAY complete and send back your survey today. We need your answers to improve bowel research and awareness.

About you

- Your gender**
 Male Female
- Your age**
 18-34 35-49 50-64 65+
- Your ethnic background**
 White (British, Irish or other)
 Black (African, Caribbean or other)
 Asian (Indian, Pakistani, Bangladeshi or other)
 Chinese (Chinese or other) Mixed
- Your education**
 Degree or higher A levels or equivalent
 GCSE/O levels Other None

Your bowel health

- Have you, a family member or friend ever suffered a bowel problem?
 Bowel cancer
 Colitis or Crohn's disease
 Constipation or faecal incontinence
 Irritable Bowel Syndrome
 Other
- If you have answered yes to the above, do bowel problems cause problems with day-to-day living?
 Yes No
- If you have answered yes to the above, do bowel problems make you/them feel isolated or unable to participate fully socially?
 Yes No

About bowel cancer risk

Apart from alcohol and smoking, there are other lifestyle factors which can increase the risk of developing bowel cancer.

- Do you know that eating too much red and processed meat increases your risk of bowel cancer?
 Yes No
- Do you know how much cooked red meat is advised per day?
 10g 90g 150g
- Do you know how much processed meat is advised per day?
 7g 70g 120g
- Do you know there is a clear link between being overweight and bowel cancer?
 Yes No
- Do you know that fat stored around the waistline seems to be significant?
 Yes No
- Do you know that there is evidence to show that leafy green vegetables, for example broccoli, are particularly protective against bowel cancer?
 Yes No
- Being physically active (up to 150 minutes per week) reduces the risk of developing bowel cancer, but by how much?
 Up to 10%
 Up to 20%
 Up to 30%

- Do you think that the NHS should provide prescriptions for exercise and lifestyle changes as well as for medicines?
 Yes No

About bowel cancer diagnosis and screening

- How many people are diagnosed with bowel cancer every year?
 More than 20,000
 More than 30,000
 More than 40,000
 - Are you aware that bowel cancer is the second biggest cancer killer in the UK?
 Yes No
 - Are you aware that bowel cancer is one of the easiest cancers to cure if caught early?
 Yes No
- The current NHS bowel cancer screening programme offers screening every two years for men and women aged 60 to 69, and in many areas has rolled this out to up to 74. A self-test kit for a stool sample is mailed in the post together with instructions on completing the test.
- Are you aware that the bowel cancer screening programme will reduce deaths from cancer by around 16%?
 Yes No
 - Have you or a family member received a kit in the post?
 Yes No
 - If you have answered yes to the above, have you completed the test?
 Yes No

- If you have not completed the test, was it because...

- I found the process of collecting the stool sample dirty and unpleasant
 I am not concerned about bowel cancer
 I found the instructions difficult to understand
 Other (e.g.) cultural reasons, religious reasons etc.)

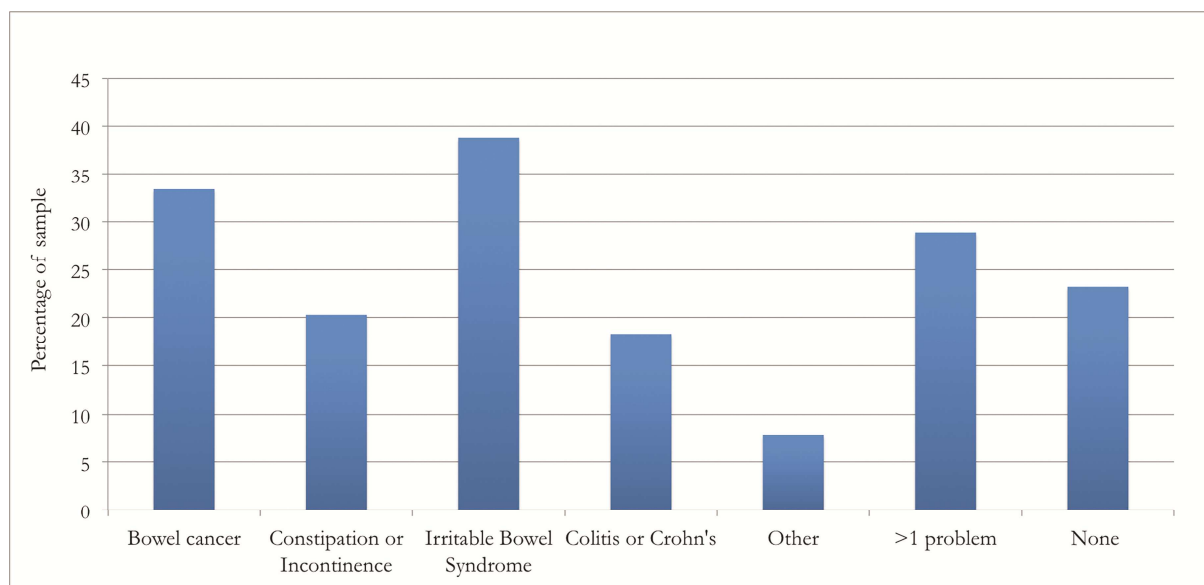
- Would you have completed the test if...

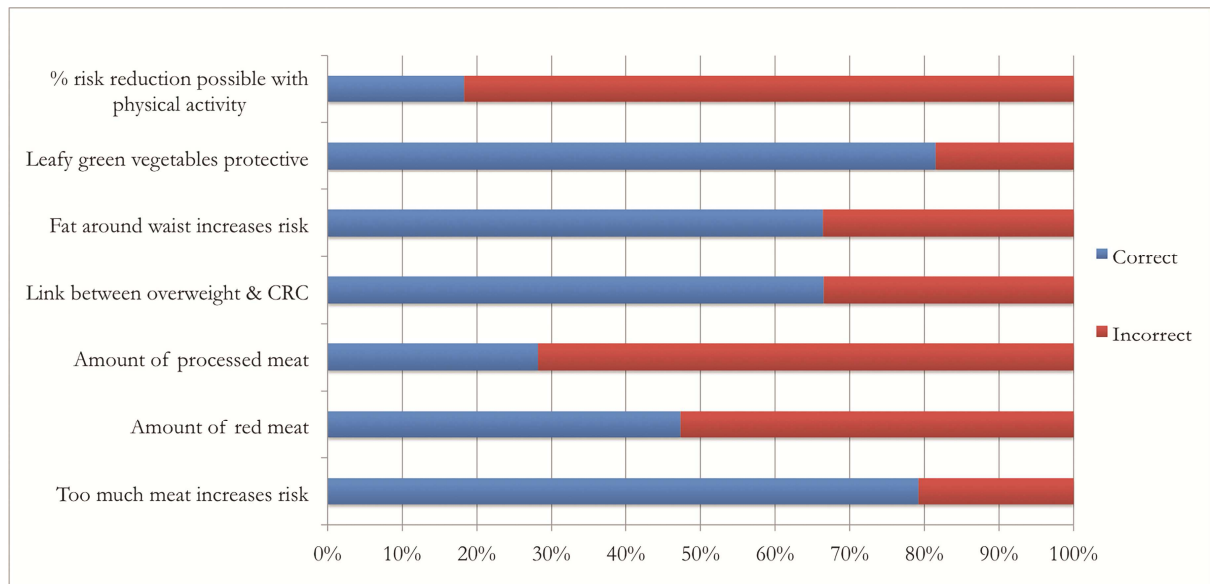
- If the method of completing the test had been less distasteful to you?
 If it had involved a blood sample only?
 If it had involved a saliva test only?

About Bowel & Cancer Research

- Do you know that Bowel & Cancer Research is a national charity funding research into bowel cancer?
 Yes No
- Do you know that Bowel & Cancer Research also funds research into all forms of bowel disease, including Colitis and Crohn's disease, Irritable Bowel Syndrome, constipation and incontinence?
 Yes No
- Bowel & Cancer Research runs a programme which involves members of the public in research, would you like more details on this?
 Yes No

If you would like to receive details please send us your name and address using the response form and freepost envelope enclosed with this mailing. A donation is not required.





Highlights

- Results show that awareness of lifestyle risk factors for CRC is affected by age and educational level.
- Initiatives are required to improve awareness of younger people since this group stand to benefit most from risk reduction.
- 45% were unaware that CRC is curable if caught early; screening promotion should focus on this message.