CHIEF SCIENTIST OFFICE

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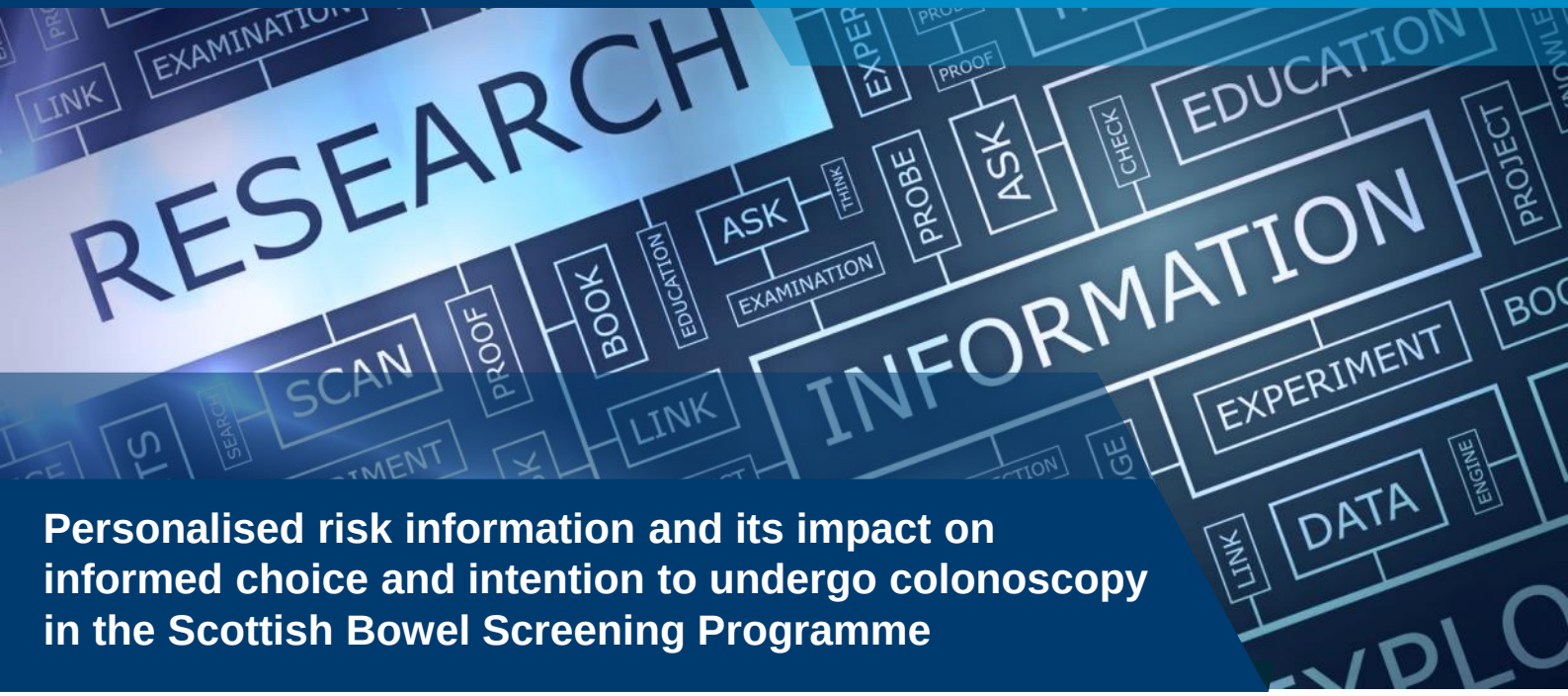
RESEARCH PROJECT BRIEFING



Personalised risk information and its impact on informed choice and intention to undergo colonoscopy in the Scottish Bowel Screening Programme

AIMS

1) To develop methods of presenting personalised information about a person's risk of having bowel cancer to people taking part in the Scottish Bowel Screening Programme, in an easy-to-understand format using infographics.

2) To measure how the different ways of presenting the risk information affect a person's level of informed choice and whether or not a person would choose to have a colonoscopy (a test where a camera tube is used to look for cancers or growths in the bowel).

3) To measure participants' responses to receiving personalised risk information, including knowledge, attitudes to screening and risk, and emotional responses including anxiety.

KEY FINDINGS

- All participants reported that they found our novel, personalised risk information materials easy-to-understand.
- More than half of participants said they would still choose to have a colonoscopy even when told they are in the lowest risk group.
- Based on our results, providing all screening participants with an informed choice based on levels of risk, around whether or not to have colonoscopy, would greatly increase demand on colonoscopy services.

WHAT DID THE STUDY INVOLVE?

Information materials displaying levels of risk for bowel cancer were developed and tested at a series of workshops with Public and Patient Involvement Representatives (PPI) members, the study team and an infographics expert. The materials developed included hypothetical bowel screening test result letters which were developed for three different groups:

1) Numerical group with three different letters saying that based on Faecal Immunochemical Test for haemoglobin (FIT) screening result, age and gender, either 1 in 40, 1 in 1600 and 1 in 3500 people like them would have bowel cancer diagnosed in the next two years. A green 'donut' style infographic with a red segment representing the ratio presented was used (Figure 1).
2) Categorical group with three different letters saying that based on FIT screening result, age and gender, they were either in the highest, moderate, or lowest risk group for having bowel cancer in the next two years. A 'traffic light' style infographic was used to highlight which group was being described (Figure 2). A short paragraph explaining what was meant by each risk group was also provided below the infographic.
3) Those randomised to the control group received one scenario letter which was representative of the current letter sent to Scottish Bowel Screening Programme participants following a positive bowel screening test.

2,767 people on the Scottish Bowel Screening Programme database were invited by letter to take part in the study. Those who returned a reply slip to say the were willing to participate were randomly allocated to one of the three study groups and sent the scenario letter/s along with information about bowel screening and colonoscopy and a questionnaire about whether they would take up the offer of colonoscopy if they received each of the letters, their knowledge about and attitudes towards bowel screening and colonoscopy and their emotional responses to receiving risk information. 10 participants from each group were also selected for telephone interview to record further responses.

Figure 2. Example numerical risk scenario letter.

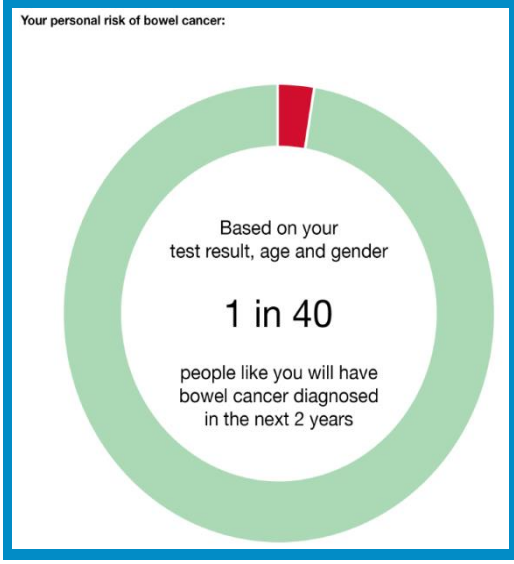
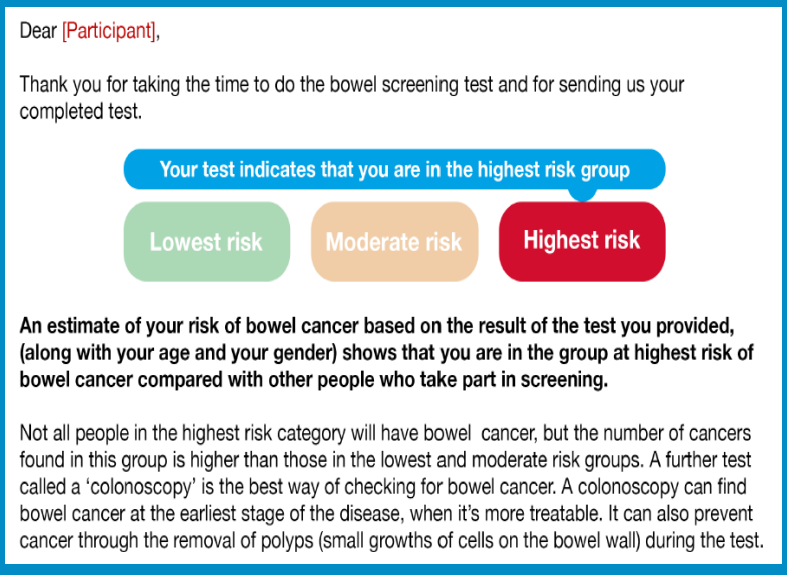


Figure 2. Example categorical risk scenario letter.



WHAT WERE THE RESULTS AND WHAT DO THEY MEAN?

434 people replied to indicate their willingness to take part. 308 returned the study materials, with 100 in the Numerical risk group, and 104 each in the Categorical risk group and the positive result letter (control) group.

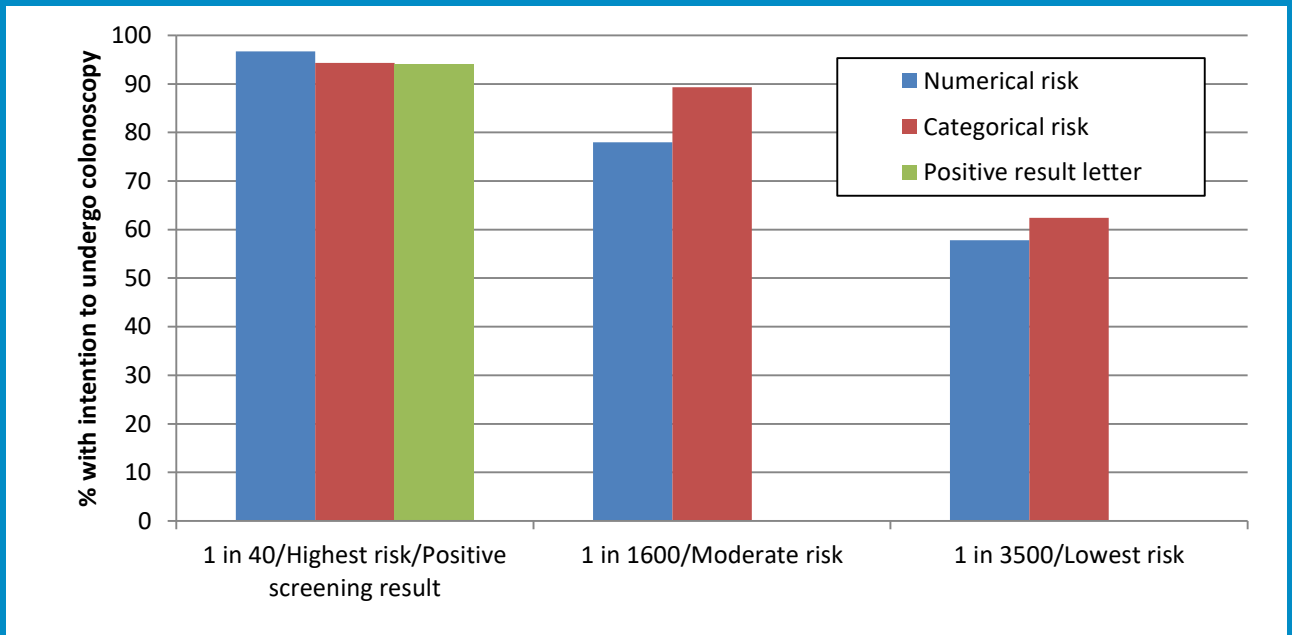
Intention to undergo colonoscopy was highest in the highest risk groups for the Numerical and Categorical study arms, but even in the lowest risk groups was greater than 50% (Figure 3). Existing data on FIT in the Scottish Bowel Screening Programme indicates that 2.5%, 38.8% and 58.7% of people would be in the highest, moderate and lowest risk groups, respectively. Using this data, our results indicate that if all participants were offered an informed choice to have colonoscopy, regardless of risk, over two-thirds of participants would opt to have the test.

Adequate knowledge of bowel screening and the risks and benefits of colonoscopy was found in ≥ 98% of participants in all three study groups.

Anxiety (measured using the six-item version of the State Anxiety Inventory with scores ranging from 20-80, with a higher score indicating a higher level of anxiety) was highest in the control group (36.8, 95% CI 33.9-39.8), compared with the numerical (32.2, 95% CI 29.8-34.6) and categorical risk information (33.8, 95% CI 30.1-35.4) groups.

All participants reported that they found the information provided easy to understand. However, 19.1% of those in the numerical risk group, 24.0% of those in the categorical risk group and 29.6% of those in the positive result letter group agreed to some extent that they found the information presented distressing. Feedback collected from telephone interviews further confirmed that the information materials developed for the study were found to be clear and acceptable.

Figure 3. Intention to undergo colonoscopy according to given risk in each study arm.



WHAT IMPACT COULD THE FINDINGS HAVE?

- Our study has shown that bowel screening participants generally respond very positively to receiving personalised risk information using infographics.
- With a growing interest in informed choice based on levels of risk in screening programmes, our finding that providing fully informed choice may not be feasible when colonoscopy capacity is limited are applicable to bowel cancer screening programmes worldwide.

HOW WILL THE OUTCOMES BE DISSEMINATED?

A full report of the research will shortly be submitted to a peer reviewed journal for publication. Presentation of the findings is also planned at national and international conferences to audiences concerned with organising and delivering bowel screening programmes.

CONCLUSION

When given the choice whether or not to have a colonoscopy , the majority of bowel screening participants will take up the offer, regardless of the level of risk they are provided with. The demand on colonoscopy services this would provide would not be manageable, with a very small number of cancers and pre-cancers detected. However, the response to the materials was very positive, suggesting that providing risk information to those in the lowest and moderate risk groups along with advice that it is not recommended that they require colonscopy at this time may be an option.

RESEARCH TEAM & CONTACT

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Additional Information

The project ended on 31st October 2019 and received £215,390 of funding from the Chief Scientist Office.