



The impact of hypothetical PErsonalised Risk Information on informed choice and intention to undergo Colorectal Cancer screening colonoscopy in Scotland (PERICCS)

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Possible conflicts of interest

- None



Background

- No existing evidence on the effects of personalised risk information on uptake of colonoscopy following colorectal cancer screening.

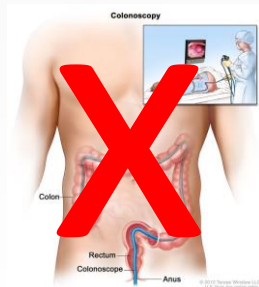


Risk of bowel perforation

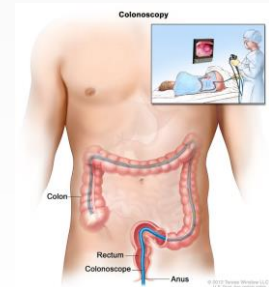
Personalised risk of having CRC

Emotional distress

Benefits of early detection



Informed decision making



Aims

- Investigate the impact of providing hypothetical personalised risk information to bowel screening participants compared to a positive/negative result letter
- Potential impact of risk information on:
 - colonoscopy services;
 - emotional responses e.g. increased anxiety about the screening process.



Methods

- No established measure to aid informed choice in colorectal screening.
- Novel personalised risk information materials developed
 - Series of workshops held with Patient and Public Involvement group and infographics expert



Risk information materials

- Three study arms:
 - 1) numerical risk information (risk categories of one in 40, one in 1600 and one in 3500)



Dear [Participant],

Thank you for taking the time to do the bowel screening test and for sending us your completed test.

Your personal risk of bowel cancer:




Risk Information Materials


- Three study arms:
 - 1) numerical risk information (risk categories of one in 40, one in 1600 and one in 3500)
 - 2) categorical risk information (highest, moderate and lowest risk)



Informed choice with FIT

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Name
Address 1
Address 2
Address 3
Postcode

12345

Date: DD MM YY
Reference No: 123456789
Enquiries to: 0000 0000 000

Dear [Participant],

Thank you for taking the time to do the bowel screening test and for sending us your completed test.

Your test indicates that you are in the highest risk group

Lowest risk Moderate risk **Highest risk**

An estimate of your risk of bowel cancer based on the result of the test you provided, (along with your age and your gender) shows that you are in the group at highest risk of bowel cancer compared with other people who take part in screening.

Not all people in the highest risk category will have bowel cancer, but the number of cancers found in this group is higher than those in the lowest and moderate risk groups. A further test called a 'colonoscopy' is the best way of checking for bowel cancer. A colonoscopy can find bowel cancer at the earliest stage of the disease, when it's more treatable. It can also prevent cancer through the removal of polyps (small growths of cells on the bowel wall) during the test.

What's a colonoscopy?

- It's usually an outpatient appointment, so you shouldn't need to stay in hospital for more than a few hours.
- A thin, flexible tube with a camera is used to examine the bowel. This means the doctor or nurse can fully examine the bowel.
- The tube reaches the bowel by passing through the bottom (back passage).



Risk information materials

- Three study arms:
 - 1) numerical risk information (risk categories of one in 40, one in 1600 and one in 3500)
 - 2) categorical risk information (highest, moderate and lowest risk)
 - 3) positive screening result letter (control group).



Study Materials

- Information/educational booklets:
 - Bowel Screening Information Leaflet
 - Colonoscopy Information Booklet
- Scenario Booklet
 - Each scenario followed by a question to measure intention to accept offer of colonoscopy
 - Informed subscore of Decisional Conflict Scale
 - Likert-style questions on planned behaviour



Study Materials

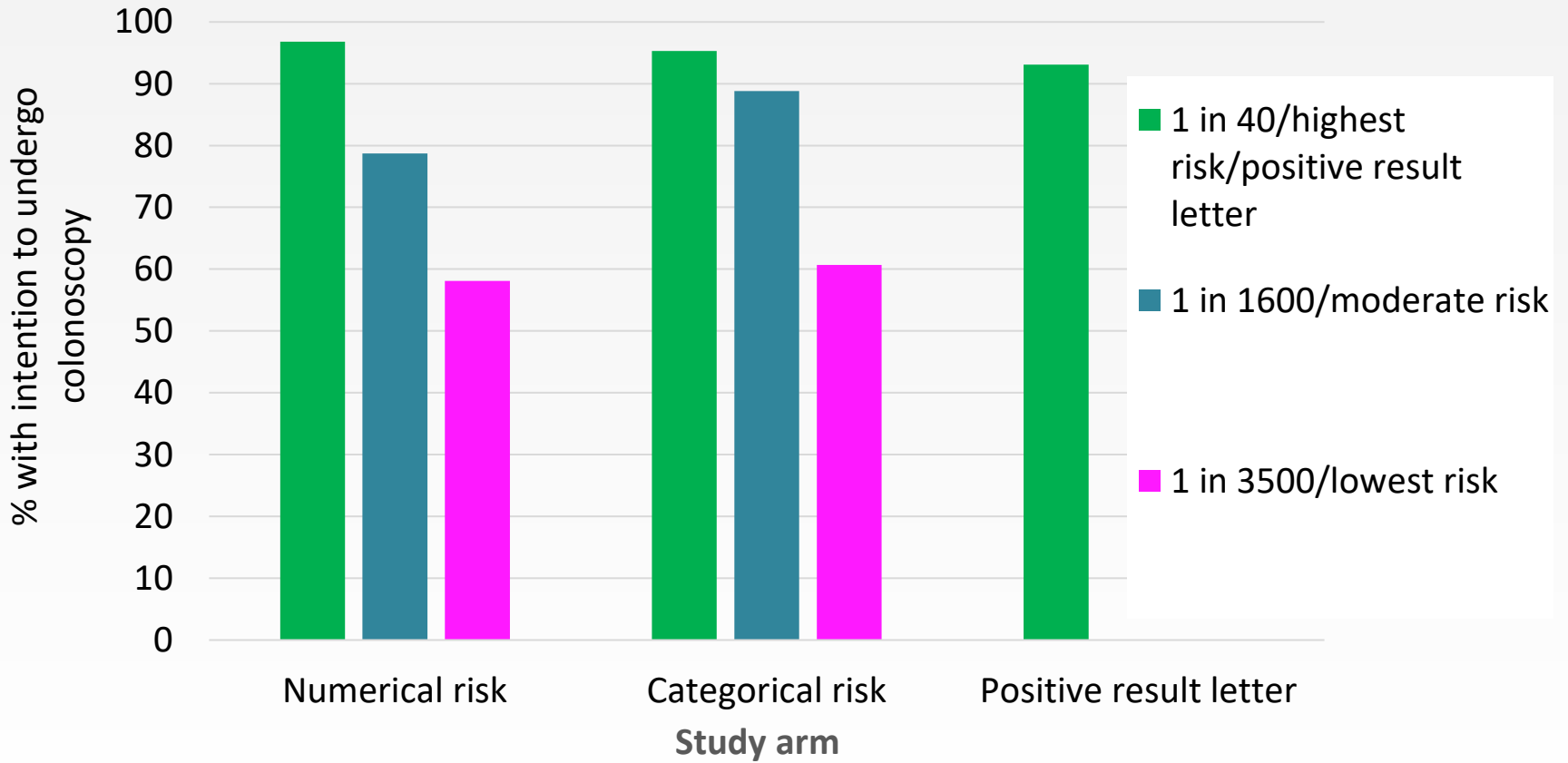
- Study Questionnaire
 - Knowledge questions around bowel screening & colonoscopy
 - Attitudes towards bowel screening & colonoscopy
 - Emotional responses
 - Ease-of-understanding/acceptability
 - Previous colonoscopy
 - Open ended question for free text



Results

- 2,767 participants invited from the Scottish Bowel Screening Programme database
- 434 agreed to participate
 - 100 from the numerical risk group (69.0%);
 - 104 from the categorical risk group (72.2%);
 - 104 from the control group (71.7%) returned completed materials





Results

- Adequate knowledge of CRC screening and the risks and benefits of colonoscopy was found in $\geq 98\%$ of participants in all three arms
- All participants reported that they found the information easy-to-understand
- 19.1%, 24.0% and 29.6% of those in the numerical, categorical and control group, respectively, reported that they found the information distressing ($p > 0.05$)
- No significant difference found in level of informed choice between the three study arms
 - Determined by combining measures of knowledge, attitudes and planned behaviour.



Qualitative Results

- 30 participants took part in telephone interviews
 - 10 from each study arm
- A further 172 completed free text section on study questionnaire
 - 59, 64 and 49 in numerical, categorical and control arm respectively.



Categorical risk arm

"For peace of mind, even although you were low risk you would say 'let's know for certain'"

Numerical risk arm

"I would like to know 'yes' you have bowel cancer or 'no' you do not have bowel cancer. I feel that telling me I have a 1 in 400 or 1 in 4000 chance of getting bowel cancer is as much use to me as being told my chances of dying as a result of a car crash or being hit by a bus; just something else to worry about!"

Categorical risk arm

"I think I understand what is meant by 'lowest risk' and 'highest risk', but 'moderate risk' is more difficult...I think I would err on the side of caution and have a colonoscopy"

Categorical risk arm

"I feel if percentages of risk and recovery were given, I could have made a more informed decision"



Categorical risk arm

“The letters would suggest everyone, regardless of risk will be offered a colonoscopy. However, if there is a “not currently at risk” group then this should be incorporated”

Categorical risk arm

“Gave me a clear understanding i.e. risk. Would prefer to know as much as possible of my situation and risk level”

Numerical risk arm

“Though I would be concerned about any future risk of cancer, I prefer an honest approach to the situation”



Conclusions

- Lowest risk information did not adequately reassure that colonoscopy was not necessary
- Applying the risk categories to existing Scottish Bowel Screening Programme data shows that if all participants were offered an informed choice to have colonoscopy, over two-thirds of participants would intend to have the test.
 - Represents an increase in the current number of screening colonoscopies performed in Scotland from approx. 14,000 per annum to approx. 400,000 per annum.
- Unmanageable demand on colonoscopy services, with a very small proportion of cancers and pre-cancers detected.



Conclusions

- However, the responses to the materials were generally very positive
 - Giving more information does not appear to make people more anxious
 - Providing risk information to those in lowest and moderate risk groups along with advice that colonoscopy is not currently recommended may be an option.
- Future research would be required to examine actual uptake.
 - Likely to be a gap between intention and behaviour



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The impact of hypothetical PErsonalised Risk Information on informed choice and intention to undergo Colorectal Cancer screening colonoscopy in Scotland (**PERICCS**)-a randomised controlled trial.

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