Reasons for non-participation in the Northern Ireland Bowel Cancer Screening Programme: a qualitative study

Supplementary Materials 1

Introduction (5 mins)
- Introduction and warm-up;
- Introduce research – the research is helping the PHA to develop its screening services. Screening is a way of helping people to find out if they are at risk of developing a disease, before it becomes obvious. If signs are found, they can be treated earlier, and this may help to stop the disease from developing.
- Explain how focus groups work – no right or wrong answers etc.;
- Explain use of digital tape;
- Explain confidentiality, anonymity and reporting procedures;
- Explain if they have any queries participants they will be provided with a leaflet at the end of the focus group session. Contact details for other help will be made available; and
- Ask each participant to introduce themselves – name, age, family etc.

Knowledge of the prevalence of cancer (warm up) (10 mins)
- Which types of cancer are you are of? – write on post it notes
- Which do you think is most common? – rank the post it notes in order
- Which types of cancers are harder to treat successfully? – pick from the post-it notes
- Which type of cancer would you be most concerned about getting?
- What symptoms are you aware of that might indicate cancer?
- What can you do to minimise the risk of cancer? Prompt - reduce alcohol, stop smoking, eat healthily 5-a-day, don’t ignore symptoms, attend screening

Attitude towards screening/ learning about disease risks and personal health status (10 mins)
- Is it better to know about your risk of developing a disease? Why?
• Would you prefer not to know until it happens? (‘Don’t ask, Don’t tell’?)
• If there was a test for (any) disease, would you try to take it? Why?/why not?
• Have you been offered any screening or test? Which ones/when?
  IF YES – did you undertake the screening/tests? Which ones
  IF YES What prompted/persuaded you to take the test/screening?
  IF NO What stopped you from taking the test/screening?
• Are there any diseases you would be too worried about to ask for a test?
  Which ones?

Knowledge of bowel cancer (5 mins)
• If not already identified – have you heard of bowel cancer?
• What do you know about bowel cancer?
  How common is it?
  What are the symptoms?
  What causes it?/How can it be avoided?
  How is it treated / How successful is treatment?

Awareness / knowledge about possibility of screening for bowel cancer (10 mins)
• Are you aware that you can be screened for bowel cancer?
  IF YES What does the screening involve?
  IF NO What do you think is involved in the screening?
  IF NECESSARY – Explain the difference between FOBt (looking for invisible blood in the faeces / ‘poo’) and colonoscopy (putting a tube with a camera inside you to see if there are any growths). Reactions?
• Brief group about the Screening Programme (show the kit and explain the procedure of being sent a card to put a sample on and posting it back to the hospital).
• Do you remember being invited to be screened for bowel cancer?
• What did you think when they received their invitations to participate in the bowel cancer screening programme?
• What, if anything, did they do?
Possible reasons for avoiding / not taking part in screening (20 mins)

- How do people feel about the procedure as we have described it?

Exercise:
Part 1: What do you think are the positive things about the screening – write on post its and rank in order of most important

Part 2: What do you think are the negative things about the screening - write on post its and rank in order of most important

- Explore each negative aspect in turn – probe the following if not identified already.
  
  Fear and avoidance
  
  Fear/denial of severity of disease/ level of threat & impact on social life;
  Don’t have any symptoms so don’t need to do it;
  Avoidance (rather not know? is this general for all screening?);
  Lack of confidence in the screening test (it would make no difference);
  Belief that disease itself cannot be prevented/ cured/ treated (it is of no value);
  Fear of follow-up investigations (e.g. colonoscopy) or of treatment; and
  Procedural/hygiene
  Distaste over notion of (FOBt) testing;
  Practical problems of conducting test – storage, timing, bowel habits.
  Religious scruples over (dealing with) waste matter;
  Other worries about hygiene (‘it is dirty’);

Views on getting test results (5 mins)

- How do you feel about getting the test results? Probe.
  
  Fear that it may be too late to do anything
  Relief that it might have been caught in time
  Shame
  Worry that next test might be painful, or lead to bad result
  Concern that the test result might be wrong

- Does this deter you from taking the screening?
What would encourage up take? (10 mins)

- If you had to try and get people like you to take part in (any) screening, what do you think would be the best way to encourage them to do it?
  
  Awareness and overcoming apprehensions
  
  Providing sex specific information about the disease and the screening programme
  
  Encouraging people to talk to someone they trust before deciding whether to participate
  
  More involvement of GP
  
  Procedural: What is anything could be done to make the process easier?

Awareness of anyone who has been screened (5 mins)

- Do you know anyone who has undertaken the bowel cancer screening?
  
  (Explain that we do not want to know names, but to see how widely this sort of experience is shared among the community)
  
- Do you know anyone who has had a positive result /bowel cancer?

Conclusions (5 mins)

- Draw conclusions and key points from the discussion
- Ask for any further comments
- Thank participants and close
- Offer leaflet for further information