FOBT invitation letter

The letter inviting patients to perform FOBT screening should contain the following information:

- **Screening information:**
  - The purpose of screening (describe the natural course taken by the disease if not detected and explain the aim of early detection, mention the different prospects depending on whether the disease is found with screening or not, specifically mention the option of not participating);
  - Who the test is for (target population, age group); and
  - The screening interval.

- **Organisational information:**
  - How to make and change the appointment when an appointment is required to pick-up the test;
  - Cost of the test (free or not); and
  - Where further information can be obtained (information services, telephone hotlines, patient groups, websites, etc.).

- **Information about the screening test:**
  - Details of the screening test that will be performed (including who performs the test, how long it will take, what the test is designed to measure);
  - How to obtain the result (mentioning the approximate waiting times); and
  - The proportion of people who may require further testing.

- **Information about the benefits of screening:**
  - Emphasise that early detection can save lives.

- **Information about the harms/side effects/disadvantages of screening:**
  - Meaning of a FOBT positive result in terms of follow-up: what is colonoscopy, benefits and possible harms of the colonoscopy, referring to colonoscopy leaflet; and
  - Fear/anxiety about cancer and screening results.

- **Information about the FOBT kit:**
  - Where to collect it; and
  - If the FOBT kit is sent with the letter, the letter should refer to the instruction leaflet and encourage participants to read it.

- **Referral to the invitation leaflet:** encouraging participants to read it.

FOBT invitation leaflet

The leaflet inviting patients to perform FOBT screening should contain the following information:

- **Screening information:**
  - The purpose of screening (describe the natural course taken by the disease if not detected and explain the aim of early detection, mention the different prospects depending on whether the disease is found with screening or not, specifically mention the option of not participating)
  - Who the test is for (target population, age group);
  - The screening interval;
  - Quality standards and quality assurance;
  - Other types of screening; and
  - Comments on people outside the recommended age group, including those at risk of colorectal cancer.

- **Colorectal cancer:**
  - Incidence;
  - Lifetime morbidity and mortality; and
  - Risk factors.

**Screening test:**
- Nature (what is it?);
- Purpose (what the test is designed to measure);
- Details of the screening test that will be performed (including who performs the test, how long it will take, what the test is designed to measure);
- Informed consent;
- How to obtain the result (mentioning the approximate waiting times);
- Meaning of the test results (What “negative”, “positive” and “unclear” mean);
- Meaning of a FOBT positive result in terms of follow-up: what is colonoscopy, benefits and possible harms of the colonoscopy (see Chapter 5 for details), referring to colonoscopy leaflet;
- Mention the proportion of people who may require further testing; and
- Reassurance about follow-up.

• **Test characteristics:**
  - False positive and false negative results (including chances of true positive, true negative, false positive, and false negative tests);
  - Positive predictive value;
  - Number needed to screen to prevent one death; and
  - Reasons why FOBT sometimes need to be repeated.

• **Benefits of screening:**
  - Mention that early detection can save lives;
  - Cancer can be found earlier/be prevented; and
  - Screening relieves fear and anxiety about cancer; peace of mind.

• **Harms/side effects/disadvantages of screening:**
  - Harms/side effects/disadvantages of colonoscopy if follow-up is required: sedation, cleansing procedure, possible complications, discomfort and pain during the colonoscopy procedure;
  - Identification and treatment of clinically unimportant tumours: the possibility of overdiagnosis; and
  - Fear/anxiety about cancer and screening results.

• **Options:**
  - Include deciding on having a colonoscopy or not (describe the natural course taken by the disease if not detected) or being not clear about what to decide (methods for clarifying and expressing values); and
  - The opportunity to request to withdraw from the programme.

Guidelines on presenting probabilities of outcomes in an unbiased and understandable way:
  - Use event rates specifying the population and time period;
  - Compare outcome probabilities using the same denominator, time period, scale;
  - Describe uncertainty around probabilities;
  - Absolute risk should be used in preference to relative risk;
  - Use visual diagrams;
  - Use multiple methods to give probabilities (words, numbers, diagrams);
  - Allow the patient to select a way of viewing probabilities (words, numbers, diagrams);
  - Allow patient to view probabilities based on their own situation (e.g. age); and
  - Place probabilities in context of other events.

**FOBT result/follow-up letter**

The letter to inform patients about FOBT screening result should contain the following information:
  • The letter should be personalised with the name of the patient and give the FOBT screening test result.
  • If the result is negative, its meaning should be explained in terms of the likelihood of having CRC and the possibility of false negatives. The screening interval should be also specified.
  • If the test is unclear, its meaning should be explained. If the directives of the screening programme are to repeat the FOBT, the letter should mention it and the patient should be invited to perform a repeat test.
  • If the test is positive, its meaning should be explained in terms of the likelihood of having CRC and possibility of false positive. The letter should refer to the colonoscopy leaflet sent with the letter that describes in detail the colonoscopy procedure and should encourage participants to read it. However, certain basic and practical information about the colonoscopy procedure, its harms and benefits, and logistic/organisational information relating to the colonoscopy appointment must be included in the letter in case a person reads just the letter and not the colonoscopy leaflet.”