

# Communication about cancer screening in the UK

Rome

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# Provision of information

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- Written or verbal
- Face to face or telephone
- Amount of detail
- Different times in the screening process

# Provision of information

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- Caution: tension exists between promoting effective forms of screening and promoting choice

Informed compliance vs Informed choice

# Written information requirements

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- Background facts and figures about cancer / screening
- Benefits and risks – balanced information / likelihoods
- Practical information e.g. appointments
- Description of procedures
- Results – meaning
- What next

# Written information requirements

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- Because of the combination of benefits and harm, individuals must receive full and accurate information to facilitate informed choice
- People must be provided with all the information they want or ought to have (GMC 1999)
  - Purpose of screening
  - Likelihood of positive and negative finding
  - Possibility of false positive and false negative results
  - Risks and benefits associated with screening process
  - Medical, social, financial implications of screening
  - Follow up plans / procedures

# Written information requirements

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- Accuracy of information relates to
  - What should be conveyed
  - How
  - Quality of studies producing the information
  - Time frame / when the data were generated

# Written information requirements

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- Should be explicitly supported by the best available evidence
  - Research based information about effectiveness of screening
  - Full and accurate information about benefits and harms
  - Promote participation in decisions about screening

# Facilitating informed choice

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- What information should be given
- How much
- How should it be framed

# Cancer screening in the UK

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- NHS Cancer Screening Programmes
  - Breast cancer
  - Cervical cancer
  - Bowel cancer (from April 2006)
- Risk management programme
  - Prostate cancer

# NHS Cancer Screening Programmes

## Evidence-based guidance/materials

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### ■ Cervical Screening

- Full guidance available (1987)
- Invitation leaflet “*Cervical Screening The Facts*”
- New guidance in press (2006)

### ■ Breast Screening

- Invitation leaflet “*Breast Screening The Facts*”
- Full guidance in preparation

# NHS Cancer Screening Programmes

## Evidence-based guidance/materials

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- Bowel Screening

- Invitation leaflet in preparation “*Bowel Screening The Facts*”
- Colonoscopy leaflet in preparation “*Colonoscopy The Facts*”

- Prostate Cancer Risk Management

- Leaflet “*PSA Testing for Prostate Cancer*”
- Revised version in preparation

# NHS Cervical Screening Programme

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- Goldsmith M, Austoker J, Bankhead C. *Improving the quality of the written information sent to women about cervical screening. Guidelines on the content of letters and leaflets.* 2006; NHSCSP Publication No. 5 (revised edition).
- Goldsmith M, Austoker J, Bankhead C. *Improving the quality of the written information sent to women about cervical screening. Evidence-based criteria for the content of letters and leaflets.* 2006; NHSCSP Publication No.6 (revised edition).

# Cervical Screening Letters

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- Invitation
- Colposcopy
- Treatment
- Normal result
- Inadequate smear
- Borderline/mild dyskaryosis
- Moderate dyskaryosis or worse

# Cervical Screening Leaflets

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- Invitation
- Abnormal result
- Colposcopy
- Treatment

# Invitation Letter Template

## Main Issues

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- Screening interval
- Eligible population
- Purpose of test
- Validity of the test
- Further tests
  - Possible reasons, likelihood

# Invitation Letter Template

## Main Issues

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- Appointment information
- Venue
- Sample taker
- Test procedure
- Test results
  - How to obtain, approximate waiting time

# Invitation Leaflet Template

## Main Issues

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- Information on cervical cancer, screening
- Nature and purpose of the test
- Reliability including information on false positives / negatives, likelihoods
- Eligible population
- Test procedure

# Invitation Leaflet Template

## Main Issues

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- Test results
  - Meaning of likely results
- Causes of abnormal results
- Pros & cons
  - Including likelihoods
- Informed choice
- Further tests (recall)
  - Likelihood, brief information on colposcopy treatment, follow-up

# Written Information

## Deriving the templates

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- Existing research evidence base
  - Systematic literature review
- Information needs of women
  - Systematic literature review
  - Focus groups
  - Interviews

# Evidence Base

## Systematic Literature Review

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- Data sources
  - 12 electronic databases 1982-2005
  - Scan selected journals
  - References of selected papers
  - Grey literature
- Quantitative and qualitative studies included

# Data extraction/synthesis

## Quantitative studies

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- Quality criteria based on Grade Working Group
  - Study design
  - Study quality
  - Consistency
  - Directness

# Data extraction/synthesis

## Qualitative studies

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- Quality criteria developed specifically for study based on
  - General Medical Council guidance
  - Centre for Health Information Quality – Quality Guidelines
  - King's Fund – Informing patients: an assessment of the quality of patient information
  - NHS Toolkit for Producing Patient Information