

Communication about cancer screening in the UK

Rome

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Provision of information

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

Provision of information

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

Informed compliance vs Informed choice

Written information requirements

- 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

- 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

- 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

- 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

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

Cancer screening in the UK

- 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

■ 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

■ 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

- 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

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

Cervical Screening Leaflets

- Invitation
- Abnormal result
- Colposcopy
- Treatment

Invitation Letter Template

Main Issues

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

Invitation Letter Template

Main Issues

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

Invitation Leaflet Template

Main Issues

- 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

- 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

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

Evidence Base

Systematic Literature Review

- 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

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

Data extraction/synthesis

Qualitative studies

- 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