Informed choice in screening programmes: do leaflets help? A critical literature review

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CRD summary
The author concluded that the most effective method of promoting informed choice was unclear and that further research is required. The review was reported clearly and the author's conclusions appear to accurately reflect the data presented. However, potential limitations in the review methods mean that it is not possible to definitively confirm the reliability of the conclusions.

Authors' objectives
To assess the usefulness of leaflets in promoting informed choice in screening.

Searching
MEDLINE, EMBASE, CINAHL and the British Nursing Index were searched from inception to 2006. Other sources searched were the Cochrane Library, the Centre for Reviews and Dissemination, and the websites of the National Screening Committee and National Institute for Health and Clinical Excellence. The bibliographies of identified studies and the Journal of Medical Screening (1995 to 2005) were handsearched and experts in the field were contacted for additional studies. Non-English language publications were excluded.

Study selection

Study designs of evaluations included in the review
Randomised controlled trials (RCTs) and controlled clinical trials were eligible for inclusion.

Specific interventions included in the review
Studies of the use of information leaflets in screening programmes were eligible for inclusion. Studies that focused on personalised risk communication were excluded. The included studies evaluated leaflets with and without videos about screening for prostate cancer, pancreatic cancer, genetic mutations and antenatal screening. The control interventions included basic leaflets, conventional information, usual care and videos alone.

Participants included in the review
Studies of adult populations being offered screening were eligible for inclusion. Studies focusing on children were excluded.

Outcomes assessed in the review
Studies that attempted to determine the contribution of leaflets to the exercise of informed choice were eligible for inclusion. Studies whose only outcome measures were increased knowledge about screening or increased screening uptake were excluded. The included studies assessed knowledge, attitudes to screening, intention to be screened, actual screening uptake, belief that patients could make an informed choice, decisional uncertainty, worry about condition targeted, and anxiety; several studies used discussion with a doctor as a proxy measure for active decision-making.

How were decisions on the relevance of primary studies made?
One reviewer (the author) selected studies for inclusion. The author did not state how the papers were selected for the review.

Assessment of study quality
The author assessed study quality using criteria developed specifically for the review: definition of the research question; appropriateness of an RCT; appropriate allocation; blinding of the participants and investigators; completeness of follow-up and potential for bias; study power; and appropriateness of outcome measures.
Data extraction
The author did not state how the data were extracted for the review, or how many reviewers performed the data extraction. For each study, the percentage of patients reporting outcomes of interest were presented, along with 95% confidence intervals (CIs) or p-values for the difference between the intervention and control groups.

Methods of synthesis
How were the studies combined?
The studies were combined in a narrative, grouped by target condition and outcome. Study details, main results and the results of the quality assessment were tabulated.

How were differences between studies investigated?
Differences between the studies were not formally addressed. The problem of comparing studies using different interventions was explored in the discussion.

Results of the review
Eight small RCTs (total of 3,743 participants) and one large cluster randomised trial (n=10,070) were included in the review.

The quality of the studies was variable and only one study met all quality criteria. Five studies described the randomisation method, four stated that assessors were blinded to the intervention, and two used intention-to-treat analysis. Five studies included power calculations, one of which was underpowered.

Knowledge about screening (7 studies): five of the 7 studies showed increased knowledge in the intervention group compared with the controls.

Screening uptake (5 studies): none of the 4 studies with screening uptake as an outcome measure found any difference between the intervention and control groups; one study showed less desire for screening in the intervention group.

Informed choice (6 studies): all 6 studies included some analysis of decision-making. Of the 4 studies that found no difference between the intervention and control groups, in one of these studies more than 40% of the participants felt that the information provided advocated screening. Of the 2 studies that found an effect, one found that the intervention group was more likely to discuss screening with their doctor, while the other found that the intervention group was more likely to feel able to make an informed choice.

Authors' conclusions
The most effective way for screening programmes to achieve informed choice was unclear.

CRD commentary
This single-author review addressed a clearly defined, relevant and underexplored research question; appropriate inclusion criteria were stated. The search strategy was extensive, but the restriction to English language publications might have resulted in the loss of some relevant data. Although the author selected studies for the review, other aspects of review methodology were not described; this leaves open the potential for reviewer error and/or bias. The quality of the included studies was assessed using criteria specifically developed for the review but the results, which were reported, were not related to the study findings. The narrative synthesis was appropriate given the apparent heterogeneity of the included studies, and details of the included studies, their main findings and the results of the quality assessment were tabulated clearly. The author's conclusions appear to accurately reflect the uncertainty in the data presented, given the caveats outlined above.

Implications of the review for practice and research
Practice: The author stated that screening programmes should not rely solely on written information, but should explore
additional ways of promoting informed choice (e.g. tailored information, web-based decision aids, semi-structured discussion).

Research: The author stated that research to develop an agreed definition of informed choice, standardise its measurement, and evaluate alternative approaches to facilitating it, is required.

Bibliographic details

PubMedID
17060352

DOI
10.1093/pubmed/fdl066

Indexing Status
Subject indexing assigned by NLM

MeSH
Databases, Bibliographic; Great Britain; Humans; Informed Consent; Mass Screening /standards; Pamphlets; Patient Education as Topic /methods; Patient Participation; Program Evaluation

AccessionNumber
12007008018

Date bibliographic record published
31/07/2007

Date abstract record published
31/07/2007

Record Status
This is a critical abstract of a systematic review that meets the criteria for inclusion on DARE. Each critical abstract contains a brief summary of the review methods, results and conclusions followed by a detailed critical assessment on the reliability of the review and the conclusions drawn.