Improving subjective perception of personal cancer risk: systematic review and meta-analysis of educational interventions for people with cancer or at high risk of cancer

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Short title: The effect of psycho-educational interventions on cancer risk perception.

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ABSTRACT

Objective: To assess the effectiveness of educational interventions in improving subjective cancer risk perception, and to appraise the quality of the studies.

Method: We conducted a systematic review and meta-analysis of randomised controlled trials and prospective observational studies. Eligible studies were identified via Medline, PsycINFO, AMED, CINAHL and Embase databases. After screening titles and abstracts, two reviewers independently assessed the eligibility of 206 full-text articles.

Results: **40** papers were included in the review; the majority of studies were conducted among breast cancer patients (n=**29**) and evaluated the effect of genetic counselling on personal perceived risk (n=25). Pooled results from randomised controlled trials (n=**12**) showed that, both in the short and long term, educational interventions did not influence level (standardised mean difference 0.05, 95% CI -0.24 to 0.34; *p*=0.74) or accuracy (odds ratio for improved risk accuracy =1.96, 95% CI: 0.61 to 6.25; *p*=0.26) of risk perception. Only one randomised controlled trial reported a short term difference in risk ratings (*p*=0.01). Of prospective observational studies (n=28), many did demonstrate changes in level of perceived risk, and improved risk accuracy and risk ratings in both the short and long term. However, only one (of 3) observational studies reported a short term difference in risk ratings (*p*<=0.003).

Conclusion: Despite favourable results from prospective studies, there was no clear evidence from randomised controlled trials to support the effectiveness of educational interventions in improving cancer risk perception. Further development and investigation of educational interventions using good quality, randomised controlled trials is warranted.

Systematic review registration: PROSPERO register (Registration number: CRD42012002861)

Keywords: **Perceived risk; cancer; oncology; psycho-educational; review.**

INTRODUCTION

People newly diagnosed with cancer require education about the disease, available treatments and the potential consequences of treatment. A review by Mills and Sullivan[1] found that effective cancer education increased patients' control and involvement in their care, reduced psychological distress, and improved adherence to treatment. Although the ultimate goal of health education interventions is to positively influence health status, the indicators of success are often changes in intermediate outcomes, such as subjective perception of personal risk ("risk perception"), which are critical to the longer-term outcomes of cancer prevention and control. Perception of cancer risk has been found to be theoretically and empirically relevant in motivating cancer screening and risk reduction behaviours.[2-4] Research by Kreuter[5 6] concluded that people who underestimate their risk of developing cancer may be less likely to engage in health-protective behaviours, whereas those who overestimate their risk may worry excessively, overdo protective behaviours, and burden the health care system. Cancer risk perception is associated with health-related quality of life, including psychological adjustment, and health behaviours.[7] For example, Waters et al[8] found that high perceived cancer risk was associated with lower mental and physical health-related quality of life. Kinsinger et al[9] observed that perceived risk of breast cancer was positively associated with depression, anxiety, and worry about cancer.

Despite the established importance of risk perception and the increasing number of educational interventions targeting risk perception for both cancer patients and people at risk of cancer, there is little research investigating the efficacy of these interventions. In 2006, a systematic review by Braithwaite and colleagues[10] examined the impact of genetic counselling for breast, ovarian, and colorectal cancer on a range of cognitive, affective, and behavioural outcomes. Based on evidence from controlled trials, the review concluded that genetic counselling does not influence risk

perception; however, other evidence from prospective studies did suggest an increase in the accuracy of perceived risk over time. More recently, Albada et al. conducted a review specifically focused on the effects of tailored information about cancer risk, and screening interventions.[11] This review found that compared to standard information, tailored information using behavioural constructs and risk factors improved level of cancer risk perception.

No reviews have investigated the impact of all types of educational interventions on cancer risk perception. The aim of this systematic review and meta-analysis was to 1) assess the effectiveness of educational interventions on subjective cancer risk perception in the short and long-term, across all types of interventions and cancers, and 2) critically appraise the quality of the included studies.

METHODS

The protocol for this review was registered in the PROSPERO register (Registration number: CRD42012002861) http://www.crd.york.ac.uk/PROSPERO in August 2012. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement guidelines[12] were followed to identify and screen publications, extract data and describe the systematic review protocol.

Inclusion criteria

Studies published in a peer-reviewed journal and that met all of the following criteria were included in the review:

- The study evaluated the impact of an educational intervention on cancer risk perception;
- The intervention was an educational intervention of any form including genetic counselling;
- The study assessed and reported personal cancer risk perception as a primary or secondary outcome;
- The intervention targeted people affected by cancer (cancer patients, cancer survivors), people who were at high or moderate risk of developing cancer, or who were referred to genetic counselling because of a personal or family history of cancer.

Exclusion criteria

We excluded studies that:

- involved only caregivers;
- were conducted only among the general population (i.e. not targeted at risk groups);
- were case studies, conference abstracts, systematic reviews or meta-analyses.

Search strategy

In January 2013, we searched international electronic bibliographic databases Medline (1950 to January 2013), PsycINFO (1806 to January 2013), Allied and Complementary Medicine (AMED) (1985 to January 2013), Cumulative Index to Nursing and Allied Health Literature (CINAHL) (1982 to January 2013) and Embase (1966 to January 2013). We also conducted hand-searches of the reference lists of included papers. With the exception of human research, the search was conducted without limitations by country, language or year. Our search strategy was developed in Medline and adapted to other databases (see supplementary table 1). In addition, in order to examine how well melanoma was captured under the broader term of "neoplasm", we conducted a complementary search using "melanoma" as a MeSH term and text word. This was done to facilitate future work in our broader melanoma research programme.

Study selection

Study selection was conducted in two distinct rounds. In the first round, one reviewer (MD) screened all titles and abstracts for non-research articles, duplicates and ineligible publications such as single case reports, letters, commentaries, conference abstracts, or those focused on other topics. Non-English abstracts were translated using Google Translator (http://translate.google.com.au/). In the second round, the full text of all remaining papers was examined independently by two reviewers (MD and CW). When there was disagreement, two external reviewers (NK and AC) were consulted and inclusion was agreed by consensus. The reference lists of all publications identified were examined for other potentially relevant papers not captured by the initial search strategy. Data were extracted using a predefined data form developed using the PICOS (participants, interventions, comparators, outcomes, and study design) approach.[12]

Appraisal and quality assessment

A specific quality appraisal tool was used for each type of study design (prospective observational or randomised controlled trial (RCT)). Methodological quality was assessed independently by two reviewers (MD and CW). For RCTs, we used the Cochrane collaboration tool for assessing risk of bias.[13] It is a domain-based evaluation which is used to critically assess six domains of bias: selection bias, performance bias, detection bias, attrition bias, reporting bias, and other bias.[13] For assessing the quality of prospective observational studies, we used the Quality Assessment Tool for Quantitative Studies,[14] which has been judged to be suitable to use for systematic reviews of effectiveness.[15] This tool includes 21 items separated into eight components: selection bias, study design, confounders, blinding, data collection methods, withdrawals and dropouts, intervention integrity and analysis.

Analysis of the effectiveness of the educational interventions

Synthesising the results of all the included studies was challenging because of the heterogeneity of study designs, populations, interventions and outcomes in the included studies. We synthesised the evidence according to how risk perception was reported in each paper (mean perceived risk, risk accuracy, risk rating), as it was assessed using different scales and presented in different ways across studies. We presented results separately for RCTs and prospective observational studies. Results for both study types were presented as forest plots where possible; however a formal meta-analysis of results (i.e. to show a pooled effect) was performed only for RCTs due to the heterogeneous prospective observational study designs. We used Cochrane software RevMan5[16] to summarise the estimates of effect and to produce figures.

RESULTS

Literature search

We identified 3386 papers through database searching and 13 additional papers were located through manual searching (Supplementary figure 1). These were reduced to 206 potentially eligible studies after removing duplicates and applying the inclusion and exclusion criteria to the titles and abstracts. After assessment of the full text of the remaining papers, **40** studies that examined the effect of educational interventions on cancer risk perception among **people affected by cancer, or at moderate or high risk of cancer, or were referred to genetic counselling because of a personal or family history of cancer, were included in the review**. Of these, **12** were RCTs and 28 were prospective observational studies, conducted in the United States (n=11), United Kingdom (n=**13**), Sweden (n=4), Australia (n=3), Canada (n=3), The Netherlands (n=2), Norway (n=1), Spain (n=1), Israel (n=1), and Denmark (n=1).

Characteristics of included studies

Randomised Controlled Trials (n=12)

Ten RCTs were conducted among breast cancer patients and two among melanoma patients (Table 1). Sample sizes ranged from 40 to 545 participants, and the mean number of participants was **248**. Of the **ten** breast cancer RCTs, four tested the effect of genetic counselling or genetic risk assessment,[17-20] one tested the effect of a pre-visit (breast cancer genetic counselling visit) educational website versus usual care,[21] one measured the effect of an alternative model of cancer genetics consultation by genetic nurse specialists versus standard service,[22] one evaluated the effect of a computer-based programme followed by genetic counselling versus standard one-on-one genetic counselling,[23] **one evaluated the impact of a psychoeducational information pack versus scientific information pack versus standard care only,**[24] one evaluated the effect of a psycho-educational group intervention[25] and one tested the effect of genetic counselling plus nurse

consultation versus standard genetic counselling.[26] Of the two interventions in melanoma education, one evaluated an intervention with interactive education, education brochure and telecommunication reminders to perform skin self-examination versus usual care[27] and one evaluated the effect of a multimedia health education programme (Skinsafe).[28]

Prospective observational studies (n=28)

Of the 28 prospective observational studies, 25 used a standard "pre and post" design[29-54] whereby all individuals were assessed before and after participation in the intervention, and three studies[43 55 56] used a different "pre and post" design whereby **two groups were given the intervention at different times and the two groups were compared at the completion of the study.** The majority (n=18) of the observational studies were conducted among breast cancer patients, two among colorectal cancer patients, one with ovarian cancer patients, one among pancreatic cancer patients and six with familial cancer patients (Table 1). Sample sizes ranged from 34 to 517 participants, and the mean number of participants was 152. Most (n=19) evaluated the effect of genetic counselling on personal perceived risk,[29 32 33 35-38 40 42-45 47-50 52 53 55] three evaluated the effectiveness of cancer education sessions,[39 51 54] one involved a cancer risk evaluation programme,[34] one was an educational support group,[46] one was a cancer genetics consultation,[31] one was an educational video intervention,[56] one was a cancer counselling and screening programme,[30] and one was an information aid.[41]

Risk perception measures

A range of self-reported measures of perceived risk were used across studies, including categorical and continuous variables, and both absolute and comparative risk estimates. Perceived risk was measured using scales of various length, ranging from 1 to 5 items; **17** studies (41%)[17 21 22 **24** 28 30 31 34 36 43 45 47 50-53 56] used a single-item measure of risk perception, eight used a two-item measure,[18 19

[26 32 39 40 49 54] six used a three-item measure,[23 33 35 37 46 48] two used a four-item measure,[20 42] two studies used a five-item measure,[29 55] and five studies did not describe the measure used to assess risk perception.[25 27 38 41 44]

Impact of cancer educational interventions on risk perception

Level of perceived risk

Six RCTs reported the impact of educational interventions on the level of risk perception; four of these were able to be summarised as the standardised mean difference between treatment group means, standardised by the standard deviation at follow-up pooled across treatment groups (Figure 1). Three of the studies reported short-term (<=3 months) effects. The pooled result indicated no short-term effect of these interventions (standardised mean difference 0.05 (95% CI -0.24, 0.34); p=0.74). Two trials reported long-term effects (>3 months); one after 6 months follow-up[20] and one after 9 months follow-up[18] (Figure 1). The pooled long-term effect was small (standardised mean difference -0.37; (95% CI -0.98, 0.24) and not statistically significant (p=0.23). There was significant heterogeneity of effect sizes between studies (χ^2= 25.73; df = 4; N=5; p<0.0001); however, it was difficult to explore sources of heterogeneity due to the small total sample.

Two RCTs[23 25] that measured mean level of risk perception were not included in Figure 1; the study by Green and colleagues[23] did not report a standard deviation, and the study by Kash et al.[25] reported a risk perception score range. Green's study[23] found high risk participants' perception of risk of developing breast cancer decreased significantly from 62 to 56 (on a scale of 0-100) (p=0.006) after either counselling or computer programme use. Kash's study[25] also concluded that the psycho-educational intervention significantly reduced perceived risk (mean perceived score decreased from 51% - 60% at baseline to 21% - 30% at 6 weeks, 6 months and 1 year; p<0.01), which had been highly overestimated by women prior to intervention use. **One study by Appleton**

et al.[24] was not clear about how they summarise risk perception so we could not include it in figure 1. Appleton study found that people who received the scientific information only experienced a significant decrease in perceived likelihood of developing breast cancer (*p*=0.039).

Figure 2 summarises the impact of the interventions on mean level of risk perception from eight prospective observational studies. Of 7 studies assessing short-term outcomes, three reported a statistically significant change from baseline level of mean perceived risk[34 35 48] and four studies[30 40 47 52] reported no statistically significant change. Over the longer term, one study reported a statistically significant change from baseline level of mean perceived risk,[39] and two studies[40 47] reported no change.

Another three studies[29 42 44] did not report standard deviations and thus could not be presented in Figure 2; however, each of these studies showed improvements in perceived risk after genetic counselling. Mertens and colleague's [44] found that patient 5-year risk perceptions decreased significantly (-11.5%; $p<0.0001$) but remained significantly higher than the objective estimates (mean difference 18.7%; $p<0.0001$). Rantala and colleague's study[29] reported a statistically significant decrease in perceived risk reported by unaffected subjects after genetic counselling ($p<0.001$). Sagi et al.[42] also found a significant decrease in perceived risk after genetic counselling ($t = 2.2$, $df = 45$, $p \leq 0.05$).

Risk accuracy

Risk accuracy was described as the level of concordance between perceived risk estimates and calculated or counselled risk estimates (objective risk). However, different epidemiological models of risk and definitions of accuracy were used across studies.

Two RCTs[17 26] assessed the association between educational interventions and risk accuracy (Figure 3). The pooled results show that in the short-term, there was no difference in risk accuracy for the intervention versus comparison group (odds ratio (OR) for improved risk accuracy =1.96; 95% CI: 0.61, 6.25; *p*=0.26). Only one randomised trial[26] reported the long-term (8 month) effect of the intervention and found no difference (OR=1.14; 95% CI: 0.53, 2.46; *p*= 0.73).

Improvements in accuracy of risk perception were observed in 8 of 10 observational studies that evaluated short-term effectiveness (Figure 4), and most of these demonstrated strong effects; for example, four studies[32 33 36 38] had an OR > 4 for improved risk accuracy. In the long-term, four studies[33 37 43 55] reported significant improvements in risk accuracy after educational intervention (Figure 4).

One prospective cohort study by Alexander et al.[54] reported subjective and objective perceived risk as median risk estimates. This study found that initially, women substantially overestimated their chance of getting breast cancer; however, after an educational intervention, perceived risk shifted closer to the calculated objective risk although remained significantly higher ($p<0.0001$).

Risk rating

Six studies (three RCTs[22 27 28] and three observational[41 49 51]) reported the proportion of participants who *believed* their risk to be moderate or high compared to the proportion whose *objective* risk was moderate or high (Supplementary table 2). Most of these studies demonstrated that at baseline, the majority of participants overestimated their risk as moderate or high compared to their objectively calculated risk. In the short term, one RCT[22] and one observational study[41] reported a statistically significant difference in risk ratings ($p=0.01$; and $p <=0.003$ respectively). Two other studies[28 49] did not report objective risk to compare with participants' subjective risk.

Predictors of change in perceived risk

Two RCTs and eight observational studies used multiple regression to identify the predictors of improvement in risk perception; Supplementary table 3 shows the statistically significant predictors that were identified. Covariates found to be associated with a change in perceived risk included baseline risk perception, age, ethnicity, and cancer-related worry, among several others. One RCT[21] and one observational study[45], not presented in the table, found that none of the tested covariates (age, baseline genetic knowledge, educational level) were significantly associated with change. Baseline perceived risk was the most strongly and consistently reported factor associated with post intervention risk perceptions across studies.

Quality assessment

The quality assessment of included RCTs was summarised in supplementary figure 2. For items related to potential risk of bias due to allocation, **nine**[17 18 20-**24** 27 28] of **12** RCTs provided a description indicating that the sequence was adequately generated and that the allocation was adequately concealed, and three studies[19 25 26] had unclear descriptions of these processes. Blinding of participants, personnel and outcome assessors was reported as present in five studies,[17-19 25 26] not adequately described in three,[20 22 23] and **four** explicitly described their study was not blinded.[21 **24** 27 28] Incomplete outcome data were adequately described in **two studies**,[21 **24**] unclearly described in nine studies[17 19 20 22 23 25-28] and not adequately described to judge risk of bias in one study.[18] For potential risk of bias from selective reporting, only one study[21] indicated that a protocol was available by providing the trial registration number. Two studies[21 23] did not indicate any other potential threats to validity, two[26 27] did not provide an adequate description to judge potential risk of bias on this item, and **eight**[17-20 22 **24** 25 28] discussed other potential risks of bias.

The quality assessment of prospective observational studies across eight domains was summarised in Supplementary figure 3. Overall, 75% of these studies were of moderate quality and 25% of weak quality; we found no studies of strong quality. “Selection bias” was the domain in which the studies performed best, and “data collection” was the worst performing domain. More than 70% of the studies used risk perception measures that were not validated.

DISCUSSION

Cancer risk perception is related to quality of life and health behaviours,[7] and the use of educational tools aimed at improving risk perception is becoming more common. The results from this review show that there is no clear evidence to support the effectiveness of educational interventions to improve subjective perception of cancer risk. Despite favourable results from prospective studies, pooled results from RCTs showed that, both in the short and long term, educational interventions did not have a statistically significant impact on level, accuracy or rating of perceived risk perception. The majority of included studies were of moderate quality and selection bias was the domain where most studies (both RCTs and observational studies) performed best.

This review is the first, to our knowledge, to summarise the impact of educational interventions for people with cancer or those at high or moderate risk of cancer, across all types of educational interventions and cancers. Most previously published reviews looked at only one type of educational intervention[10 11 57-59] such as genetic counselling or focused on one type of cancer.[60] One strength of our review was the inclusion of all study designs, as both RCTs and observational studies provided a different perspective. The diversity of educational interventions and risk perception summary measures from the included studies means that some caution is needed in the interpretation of the pooled data. To address this issue, we classified risk perception using three end points (level of risk perception, risk accuracy and risk rating) and we also separated short and long term effects where appropriate. However, our pooled RCT results consistently showed that cancer educational interventions do not have a statistically significant impact on perceived risk.

Our review also has several limitations. First, a search of the grey literature, particularly conference abstracts and unpublished theses, was not conducted, so publication bias could not be completely eliminated. Second, there was an overrepresentation of patients with breast cancer and therefore of

women. The generalisability of results to other types of cancer and to men is unclear. Third, in our quality assessment, we relied on information about methodology as reported in the articles. For observational studies, information about confounding and blinding was often missing; we then scored these studies as "moderate" methodological quality without contacting authors for verification. Fourth, some RCTs in our review could not be pooled with results from other studies because of missing data or different measures. Omission of these studies may have influenced the overall pooled results and thus the conclusions of the review. To provide more information about these individual studies, we included brief details on their findings in our manuscript text. Finally, when examining risk accuracy, different methods for defining, measuring and analysing the data were used across studies, influencing our ability to compare changes from baseline.

Unlike the RCTs, many of the prospective observational studies included in this review demonstrated statistically significant improvements in the level, accuracy and rating of perceived risk. It is unclear why there was a discrepancy between the results of RCTs and observational studies. Compared to RCTs, observational studies are considered more prone to bias, such as confounding and publication bias,[61] so we cannot exclude the possibility that bias influenced the observed effects in the observational studies. However, two studies published in The New England Journal of Medicine in 2000 found that observational studies and RCTs overall produced similar results.[62 63] The authors of these findings cast doubt on the ideas that "observational studies should not be used for defining evidence-based medical care" and that RCT' results are "evidence of the highest grade." [62 63] A 2001 study published in the Journal of the American Medical Association concluded that "discrepancies beyond chance do occur and differences in estimated magnitude of treatment effect are very common" between observational studies and RCTs.[64] Another possible explanation could be that the types of interventions differed somewhat across the two study designs; as a higher proportion of the observational studies (68%) used genetic counselling interventions,

compared to 36% of RCTs. Previous systematic reviews and meta-analyses have shown that genetic counselling may be effective in improving risk perception,[59] particularly for breast cancer risk.[57 58] However, a systematic review by Braithwaite et al.[10] found that although genetic counselling improved knowledge of cancer genetics it did not alter the level of perceived risk. Similar to our study results, they found evidence of effectiveness from observational studies but not from RCTs.[10]

Perception of cancer risk has been reported to be relatively resistant to change over time.[65 66] This could be explained by two factors: first, people often find information on health risks difficult to understand.[67 68] According to the UK National Cancer Institute,[69] people do not always have a clear understanding of the risks of cancer, or of the likelihood of various outcomes of cancer screening tests and treatments. This could be due to the complexity that is often inherent in information about risk, as well as the need for adequate numeracy and literacy skills to understand the information. Second, communication of risk information to consumers requires clear presentation and wording, however, there is no consensus as to which format is most effective in terms of facilitating patient understanding of risk information.[67]

In this review there was an array of educational intervention formats ranging from standard genetic counselling to information aids. The majority of interventions focused on genetic counselling with an informational approach delivered by genetic counsellors, clinical geneticists, nurses or surgeons. A few studies used a combination of educational components and psychological support, or were solely psychological in nature (as outlined in Table 1). Furthermore, few studies had a well-articulated, theoretical basis on which the intervention was designed; only three studies[25 46 49] relied on the cognitive restructuring, emotional support, coping, and common sense model. It is likely that the differences in the format and design of the interventions contributed to the variation in our review results. Further studies

should ideally base their intervention on a psychological framework, as this may be useful in understanding the way people form personal perceived risk beliefs.

Many studies in this review used single-item measures of risk perception. This is consistent with the findings of a recent review by Tilbert et al.[70] which discussed the one dimensional character of risk perception measures (i.e. measuring magnitude or frequency of risk, but not both). In this review, it is not known to what extent some of the heterogeneity or non-significant results are related to the measure used to assess perceived risk. However, it is clear that standardising and validating multi-dimensional perceived risk measures would be of benefit to the field, particularly when comparing outcomes across studies.

Cancer patients or people at moderate or high risk of cancer often overestimate their risk of developing cancer. While acknowledging that there is still uncertainty about the accuracy of objective cancer risk estimates, there is evidence that improving cancer risk perception has several health benefits. Previous research by Hopwood concluded that an understanding of a person's risk perception, which is grounded in knowledge of his true risk, is necessary for risk management and decision making.[71] Evaluating risk accuracy is also important in the sense that it can encourage more appropriate health care behaviours, as people who overestimate their risk may perform excessive preventive strategies whilst under-estimators may have poor preventive health behaviours. In addition, risk information can be useful for the clinician to facilitate discussions regarding risk management, screening and prevention.[72 73]

Analyses of predictors of change in risk perception indicated that several variables such as baseline risk perception, age, ethnicity, and cancer-related worry were associated with changes in risk perception. Our findings are similar to a review of perceived risk and breast cancer screening,[74] which found weak but statistically significant associations between perceived risk and age, ethnicity

and breast cancer worry. Information about which factors predict changes in perceived risk could help clinicians and researchers tailor the design of interventions that are relevant to and appropriate for particular groups.

Although this review was based on a limited number of studies with a wide range of interventions, based on our results we would not recommend broad use in clinical practice of educational interventions to improve cancer risk perception. Despite favourable results from prospective studies, there was no clear evidence from RCTs to support their effectiveness.

Many challenges remain in improving cancer risk perception. Our review shows that measurement of perceived risk is often one-dimensional, non-standardised and reliant on the use of non-validated measures. Further research should focus on the development of new measures for cancer risk perception and test whether a multidimensional measure, combining different elements of risk perception, is feasible and adequate. Risk accuracy appears more amenable to change than mean perceived risk or risk rating, but this also needs further investigation. As demographic characteristics and psychosocial factors influence changes in perceived risk, future studies should integrate these factors into the design and implementation of educational interventions. Most of the published literature has focused on breast cancer, so studies in other cancers and particularly among men and people of diverse socioeconomic and cultural groups would help to assess the generalisability of findings. Finally, given the promising results from many observational studies with "pre and post" study designs, further investigation of well-designed educational interventions using good quality, randomised controlled trials is warranted. These future research directions will help to clarify the effectiveness of educational interventions for improving cancer risk perception.

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Table 1: Characteristics of included studies

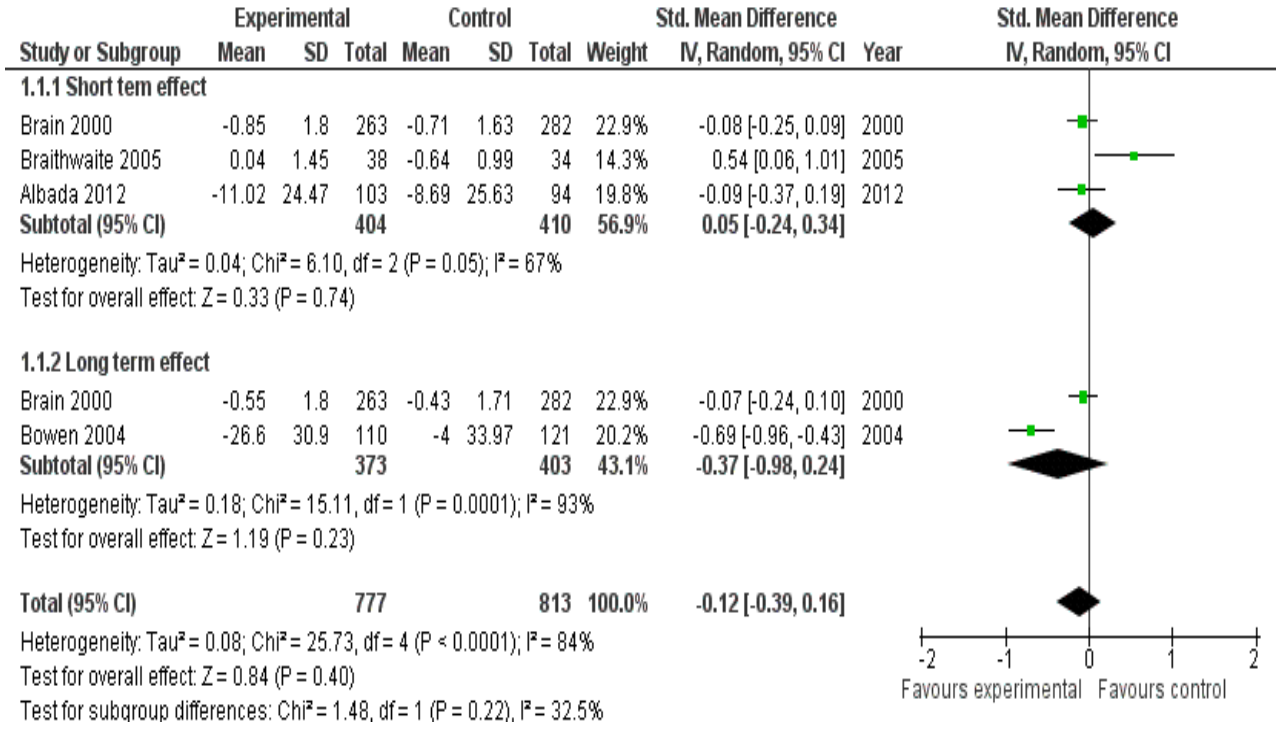
Reference	*Country/Region*	*Type of cancer*	*Type of intervention*	*Participants*	*N (Baseline)*
			Randomised Controlled trials		
Albada 2012[21]	Netherlands	Breast	Pre-visit educational website (E-info gene) vs. usual care (brief standard pre-visit leaflet).	Women attending a genetic counselling clinic for breast cancer.	197
Appleton[24]	**United Kingdom**	**Breast**	**Psychoeducational (scientific and pschosocial information) written information pack vs. Scientific information pack vs. standard care only.**	**Women attending the Ardmillan Familial Breast Cancer Clinic**	**163**
Aneja 2012[27]	United States	Melanoma	Intervention with interactive education and telecommunication reminders vs. usual care	Participants from dermatology clinics with low or high risk of melanoma.	210
Bowen 2004[20]	United States	Breast	Individual genetic counselling vs. group psychosocial counselling vs. delayed intervention.	Participants were recruited from among family members of women with breast cancer.	348
Brain 2000[18]	United Kingdom	Breast	Multidisciplinary genetic assessment vs. surgical assessment.	Women residing in Wales from two family cancer clinics.	545
Braithwaite 2005[19]	United Kingdom	Breast	GRACE (genetic risk assessment in the clinical environment) tool vs. genetic risk counselling.	Women with a family history of breast cancer.	72
Fry 2003[22]	**United Kingdom**	Breast	Novel community-based service vs. standard regional service.	Women referred to the regional clinical genetics department for breast cancer genetic risk counselling.	373
Glazebrook 2006[28]	United Kingdom	Melanoma	Multimedia health education programme (Skinsafe) vs. control.	Patients at high risk of developing melanoma and attending family practices within Nottinghamshire.	459
Green 2004[23]	United States	Breast	Computer based programme followed by genetic counselling vs. standard one-on-one genetic counselling.	Women with personal or family histories of breast cancer recruited from outpatient clinics.	211
Kash 1995[25]	United States	Breast	Psycho-educational group intervention vs. control	Women at high risk of breast cancer.	40
Lerman 1995[17]	United States	Breast	Breast cancer risk counselling vs. general health counselling.	Women with family history of breast cancer identified by a relative who was	200

				under treatment for breast cancer at a comprehensive cancer centre.	
Roshanai 2009[26]	Sweden	Breast	Standard genetic counselling + nurse consultation vs. standard genetic counselling alone.	Women attending the cancer genetic clinic of Uppsala University Hospital	163
			Observational studies		
Alexander 1995[54]	United States	Breast	90 minute breast cancer educational session with general internist	Women at high risk of breast cancer who participated in the Tamoxifen Breast Cancer prevention trial.	59
Bish 2002[40]	United Kingdom	Breast/ovarian	Genetic counselling	Women who have been treated for breast or ovarian cancer and unaffected women referred to the Department of Clinical Genetics for genetic counselling.	181
Bjorvatn 2007[35]	Norway	Breast/ovarian	Genetic counselling	People receiving counselling for cancer risk at the genetic outpatient clinics of in three university hospitals in Norway.	213
Cabrera 2010[53]	Spain	Breast	Genetic counselling	Participants with familial history of breast cancer who were referred for genetic counselling at a hospital in Barcelona.	212
Codori 2005[52]	United States	Colorectal	Genetic counselling	Adults at increased risk of HNPCC due to a family history of colorectal cancer.	101
Collins 2000[51]	Australia	Colorectal	1 hour session at a family cancer clinic + follow up letters outlining the issues discussed in the session	Individuals referred to a family cancer clinic by their GPs, family members or self referred.	126
Cull 1998[56]	United Kingdom	Breast	Educational video before clinic consultation	Women newly referred to a breast cancer family clinic.	128
Evans 1994[55]	United Kingdom	Breast	Genetic counselling +population risk information	Women who were referred to a genetic clinic for counselling.	517
Gagnon 1996[39]	Canada	Breast	Special surveillance breast programme (20 minute session with a breast surgeon)	Women who made an appointment at the Memorial Sloan Kettering cancer Centre special surveillance breast	94

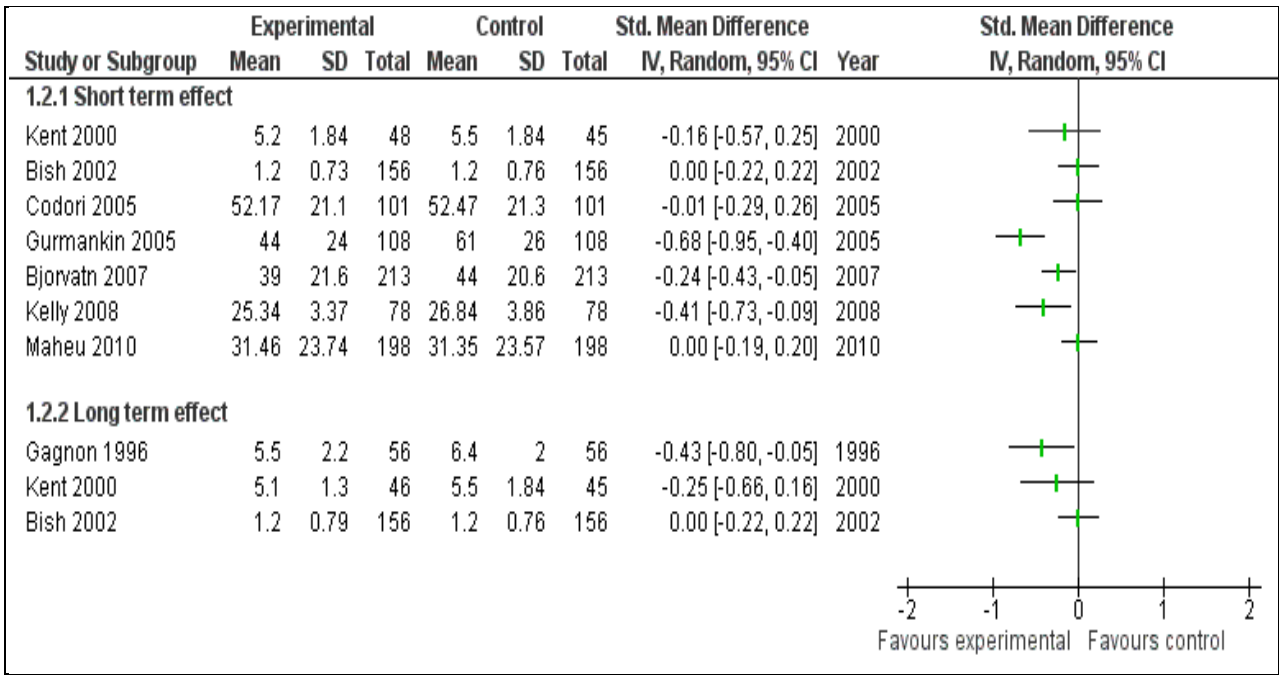
				programme (a programme for women at high risk of breast cancer).	
Gurmankin 2005[34]	United States	Breast	Cancer risk evaluation programme including genetic counselling and testing	New patients visiting the University of Pennsylvania's breast and ovarian cancer risk evaluation programme.	108
Hopwood 1998[38]	United Kingdom	Breast	Genetic counselling	Women with 2 fold or greater risk than the population referred to the family history clinic for the first time by their GP or hospital clinician	158
Hopwood 2003[33]	United Kingdom	Breast	Genetic counselling	Women with calculated lifetime breast cancer risk to age 80years of 1 in 6, attending the Family History Clinic in South Manchester	158
Hopwood 2004[50]	United Kingdom	Familial cancers: breast 75%, bowel 17%, ovary 9% and other 2%.	Genetic counselling	Individuals attending cancer genetic risk counselling for the first time.	162
Kelly 2005[49]	United States	Breast	Genetic counselling + testing + face to face meeting for test result disclosure.	Women of Ashkenazi Jewish descent with a family history or personal history of breast cancer.	99
Kelly 2008[48]	United States	Ovarian	Genetic counselling + testing + face to face meeting for test result disclosure.	Women of Ashkenazi Jewish descent with a family history or personal history of ovarian cancer.	78
Kent 2000[47]	United Kingdom	Breast	Genetic counselling	Asymptomatic women referred by their GP to the Northern General Hospital Breast Cancer Family History Clinic Sheffield.	69
Landsbergen 2010[46]	The Netherlands	Breast	Educational support group	Women with a BRCA mutation.	34
Liden 2003[32]	Sweden	Breast, ovarian, colorectal	Genetic counselling	Individuals referred by their GP or oncologist who are attending genetic counselling at the oncogenetic outpatient clinic at the University hospital, Uppsala.	77

Lobb 2004[31]	Australia	Breast	Breast cancer genetics consultation	Women from families at high risk breast cancer attending their first consultation at a familial cancer clinic within Australia before genetic testing.	158
Maheu 2010[30]	Canada	Pancreatic	Pancreatic cancer counselling and screening programme	Individuals with a family history of pancreatic cancer participating in counselling and individuals with a BRCA2 mutation participating in a screening programme.	198
Meiser 2001[45]	Australia	Breast	Genetic counselling	Women with a family history of breast cancer who approached familial cancer clinics in five Australian states between November 1996 and January 1999.	218
Mertens 2008[44]	United States	Breast	Oncologist-based counselling	Patients referred for assessment of breast cancer risk at a high risk clinic of a comprehensive breast cancer.	81
Mikkelsen 2007[43]	Denmark	Breast	Genetic counselling	Women at risk of breast cancer referred for genetic counselling by their physician.	213
Nordin 2002[36]	Sweden	Breast, ovarian, colorectal	Genetic counselling	Subjects referred for genetic counselling regarding risk of breast, ovarian or colorectal cancer at the oncogenetic outpatient clinic at Uppsala University Hospital.	63
Rantala 2009[29]	Sweden	Breast, ovarian, colorectal, endometrial, gastric	Genetic counselling	Patients referred to oncogenetic counselling for breast, ovarian, colorectal, endometrial, gastric cancer at the Karolinska University Hospital.	215
Sagi 1998[42]	Israel	Breast	Genetic counselling	Women attending a genetic clinic because they have a family history of breast cancer.	60
Warner 2003[41]	Canada	Breast	Breast cancer information aid (booklet and audiotape)	Women with a family history of breast cancer.	203

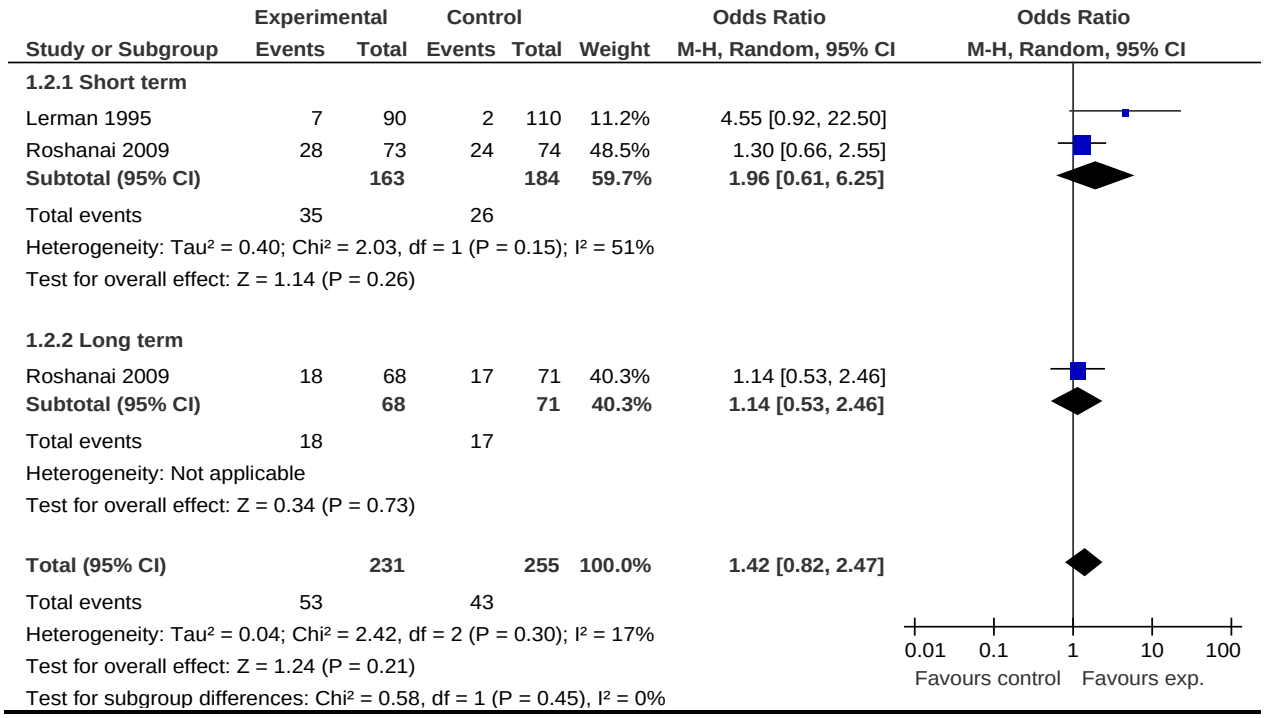
Watson[37]	United Kingdom	Breast	Genetic counselling	Women with a family history of breast cancer attending a cancer genetics clinic for counselling.	268



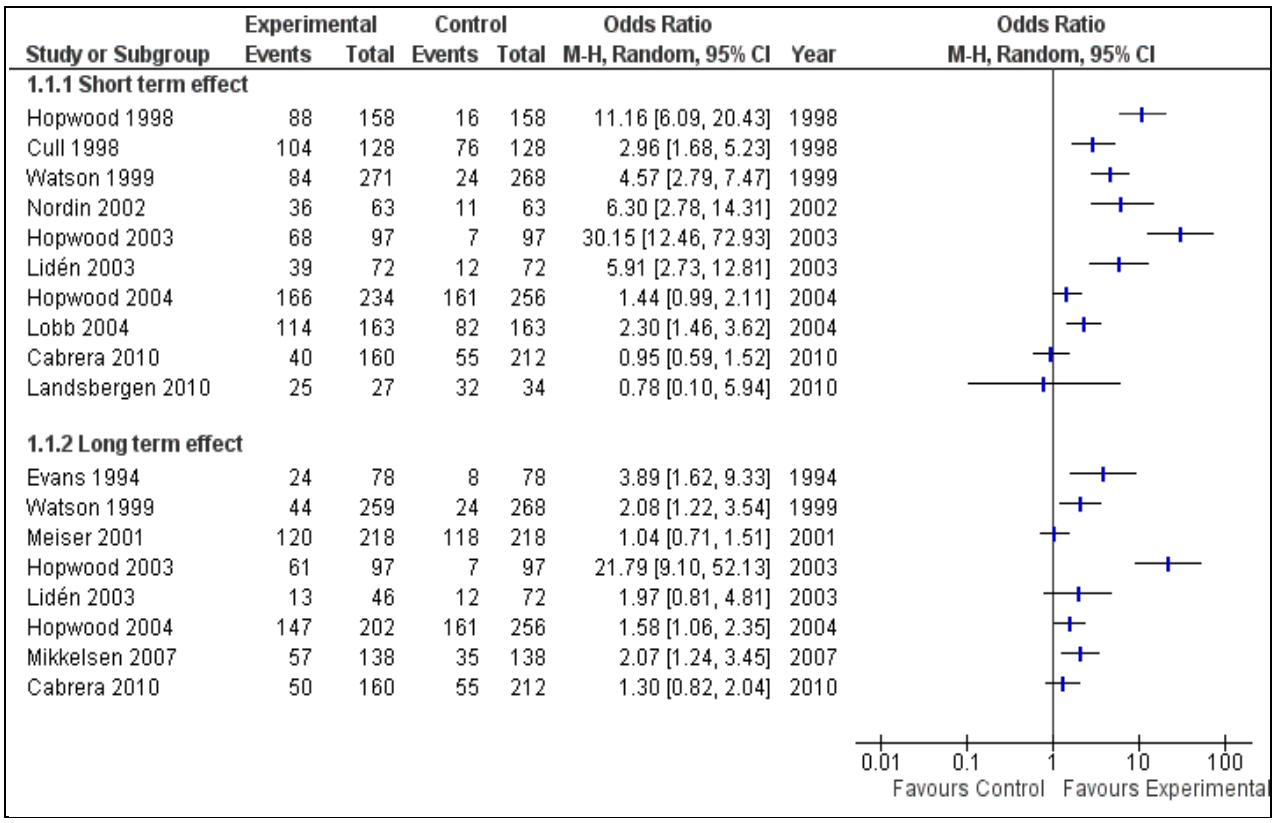
<u>Figure 1 legend</u>: Forest plot of the effect of educational interventions on mean perceived risk in RCTs in the short and long term. We stratified according to the length of follow-up, defined as short term (<=3 months) or long term (>3 months). Effectiveness was defined by the standardised mean difference between treatment group means, standardised by the standard deviation at follow-up pooled across treatment groups. A positive difference indicates increased mean risk perception in the intervention group relative to the comparison group. Perceived risk could increase or decrease but the measure of effect is whether the education intervention changed risk perception. Standardized differences are pooled using random effects chosen because of differences between the trials in interventions and scales.



<u>Figure 2 legend</u>: Forest plot of the effect of educational interventions on perceived risk in observational studies in the short and long term. We stratified according to the length of follow-up, defined as short term (<=3 months) or long term (>3 months). Effectiveness was defined by the standardised mean difference, between baseline and post-clinic means, standardized by the standard deviation at follow-up pooled across groups. A positive difference indicates an increased mean perceived risk post-intervention relative to baseline. Due to heterogeneous study designs, pooled effects are not presented.



<u>Figure 3 legend</u>: Forest plot of the effect of educational interventions in RCTs on risk accuracy in the short and long term. We stratified according to the length of follow-up, defined as short term (<=3 months) or long term (>3 months). Effectiveness was defined by the difference in risk accuracy (%), between groups. An odds ratio of greater than 1 indicated increased accuracy in risk perception. Standardized differences were pooled using random effects.



<u>Figure 4</u>: Forest plot of the effect of educational interventions on risk accuracy in observational studies in the short and long term. Results are stratified according to the length of follow-up, defined as short term <=3 months or long term >3 months. Effectiveness is defined by the difference between baseline and post-intervention risk accuracy (%). An odds ratio of greater than 1 indicates increased accuracy in risk perception. Due to heterogeneous study designs, we did not present the pooled effects.

Supplementary table 1: Search strategy in Medline

Question components and relevant search terms	Type of terms	
	Free text	*MeSH*
The population: People affected by cancer or at moderate/ high risk of cancer		
1. exp. Neoplasms		x
2. Neoplasm*.tw.	x	
3. cancer*.tw.	x	
4. tumo?r*.tw.	x	
5. ((neoplasm*ORcancer*OR tumo?r*)adj3(relapse* OR recurrence*)).tw.	x	
6. or/1-5		
Interventions: Educational interventions		
7. education/		x
8. counselling/		x
9. exp. patient education/		x
10. patient education handout/		x
11. (health adj3 education).tw	x	
12. ((education*)adj3(intervention* OR programme?e* OR tool* OR strateg*)).tw.	x	
13. ((patient*)adj3(information* OR instruction* OR training OR toolkit OR website OR handout)).tw.	x	
14. or/7-13		
Outcomes: risk perception, risk knowledge		
15. exp risk/		x
16. ((risk*) adj3(understanding OR perception OR communication OR counsel?ing OR presentation OR recall OR accuracy OR knowledge OR education)).tw.	x	
17. ((perceived OR subjective) adj3 (risk*)).tw.	x	
18. or/15-7		
19. and/6,14,18		

Supplementary table 2: Effect of educational interventions on risk ratings

Reference	Outcome	Time points	Participants		% perceived their risk to be moderate or high	% objective risk moderate or high	P-value
			Group[1]	Sample			
Randomised controlled trials							
Aneja 2012[27]	Perceived risk of melanoma	Baseline	I	112	67.5	93.8	
			C	98	Not reported	93.8	
		3 month	I	71	77	93.8	Not reported
			C	61	Not reported	93.8	
Fry 2003[22]	Perceived risk of breast cancer	Baseline	I	188	96	55	
			C	185	97	72	
		4 week	I	129	92	59	0.011
			C	147	92	77	
		6 month	I	123	91	59	NS[7]
			C	140	92	78	
Glazebrook 2006[28]	Perceived risk of melanoma	Baseline	I	259	21.4[2]	Not reported	
			C	330	21.4[2]	Not reported	
		6 month	I	214	No change	Not reported	NS[7]
			C	245	No change	Not reported	
Observational studies							
Collins 2000[51]	Perceived risk of bowel cancer[3]	Baseline		157	91[5]	79[6]	
		3 week		126	82[5]	79[6]	Not reported
Kelly 2005[49]	Perceived risk of breast cancer[4]	Baseline			78.5[6]	Not reported	
		1-3 month			67.4[6]	Not reported	Not reported
Warner 2003[41]	Lifetime perceived risk of breast cancer	Baseline		160	94	61	
		After reviewing the aid		160	62	61	<=0.003[8]

[1] I= Intervention group, C=Control group
[2] An overall rate was provided for all participants, we assumed the rates were the same in the intervention and control groups
[3] Perception of risk of developing bowel cancer compared to the general population
[4] Perception of risk of developing breast cancer compared to the general population
[5] Perceived risk of bowel cancer higher than the general population
[6] Objective risk of breast cancer higher than the general population
[7] NS= not statistically significant
[8] Two *P* values were provided: for moderate risk group (p=0.001) and high risk group (p=0.003).

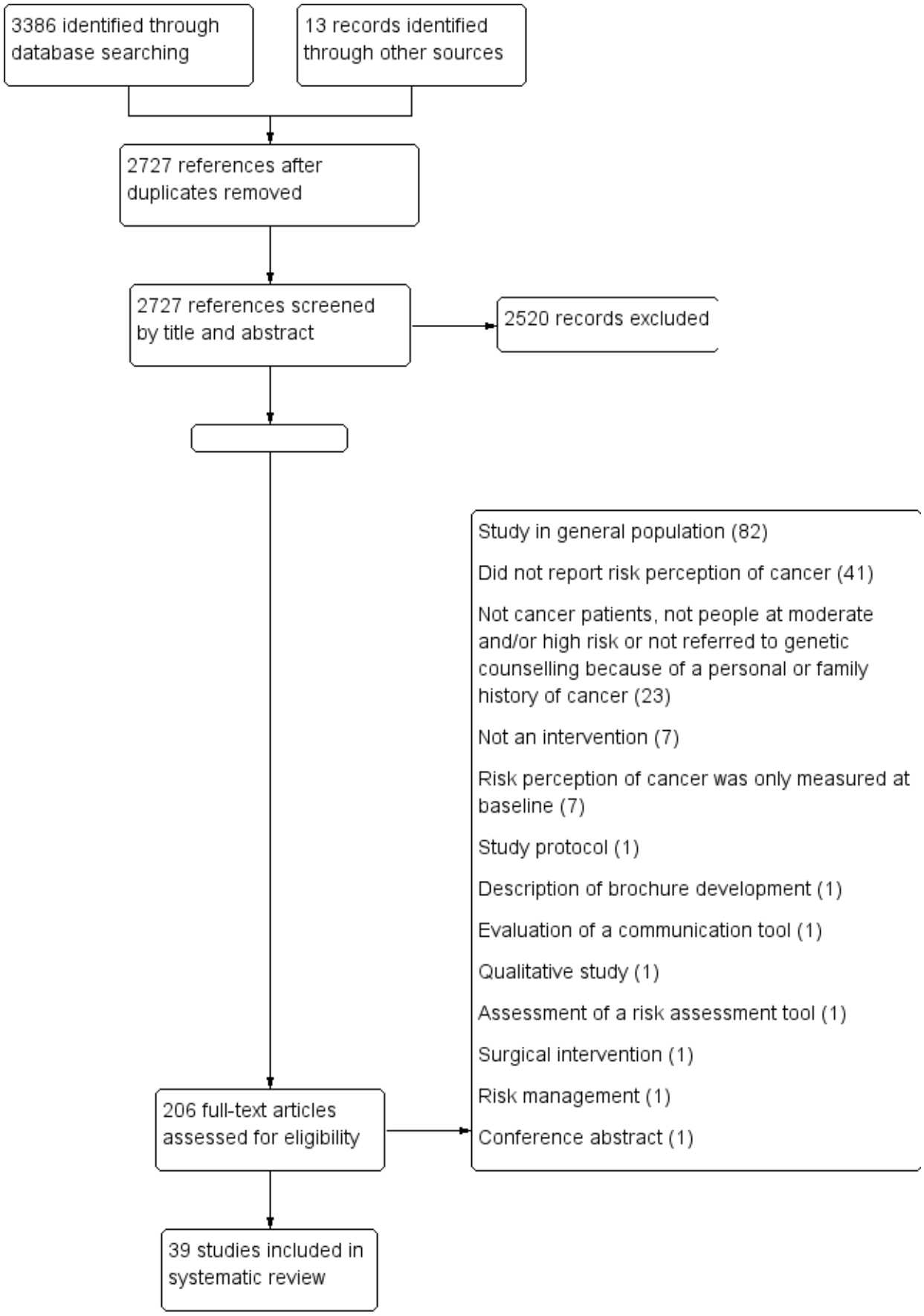
Supplementary table 3: Predictors of change in risk perception

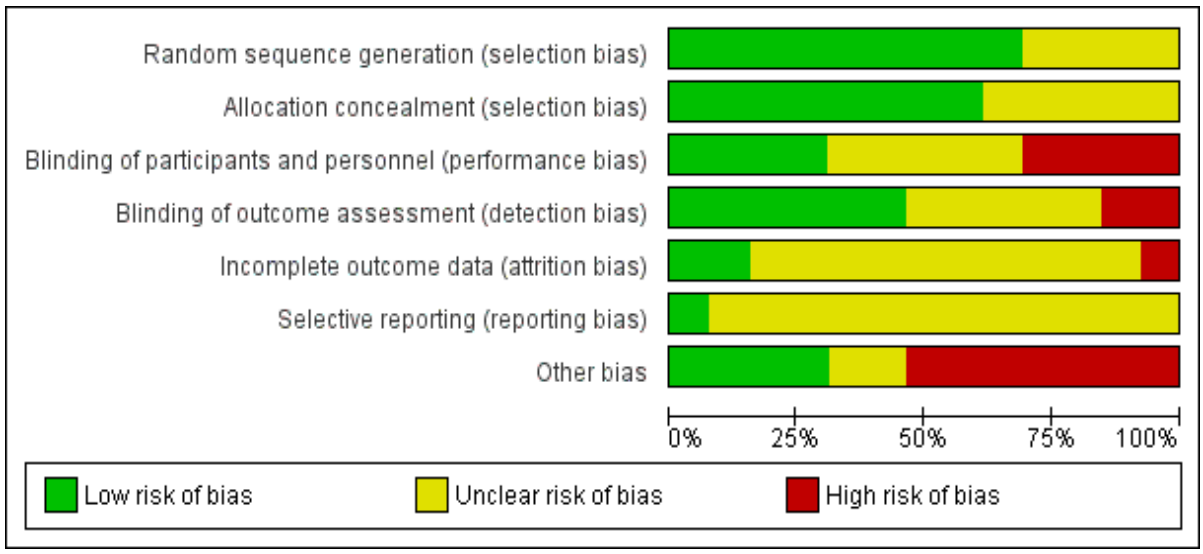
Reference	Dependant variable	Predictors variables	βeta	P-value	Odds Ratio (95% CI)
		Randomised Controlled Trials			
Bowen 2004[20]	Change in perceived risk	Lifetime Gail[1] risk score	0.67	0.02	
		Baseline perceived risk	0.5	0.001	
		Baseline anxiety symptoms	5.4	0.04	
		Genetic counselling arm	6.1	0.001	
		Genetic/psychosocial arm	8.0	0.001	
Lerman 1995[17]	Improvement in risk comprehension	Treatment group	1.25	0.01	3.49 (1.28; 9.48)
		Baseline breast cancer preoccupation	-0.14	0.02	0.87 (0.77; -0.98)
		White women	-1.09	0.05	0.34 (0.11; -0.99)
		Observational studies			
Codori 2005[52]	Change in perceived risk	Higher baseline risk perception	-0.4	P<0.0001	
		Older age	-0.4	0.006	
		Higher estimated objective risk	-0.3	0.04	
Gurmankin 2005[34]	Accuracy of breast cancer risk perception	Pre-counselling worry	7.31	0.01	
		Higher education	34.15	0.05	
Kelly 2008[48]	Change in subjective risk of ovarian cancer	Survival time		0.009	
		Older age		0.001	
Lobb 2004[31]	Accuracy of breast cancer risk perception	Receiving a written summary of the genetic counselling session		0.02	2.61 (1.14; 6.02)
Maheu 2010[30]	Level of risk perception	Baseline levels of risk perception		P<0.001	
Mikkelsen 2007[43]	Inaccurate risk	Risk communicated in words			5.50 (1.88; 16.10)

	perception	only		
		Inaccurate risk perception at baseline		5.07 (2.07; 15.79)
		Presence of a familial mutation		4.38 (1.32; 14.48)
		Having one or more daughters		2.68 (1.02; 7.05)
Mertens 2008[44]	Patient-perceived 5-year risk	Pre-counselling patient-perceived risk	P<0.0001	
		Counselling oncologist	0.003	

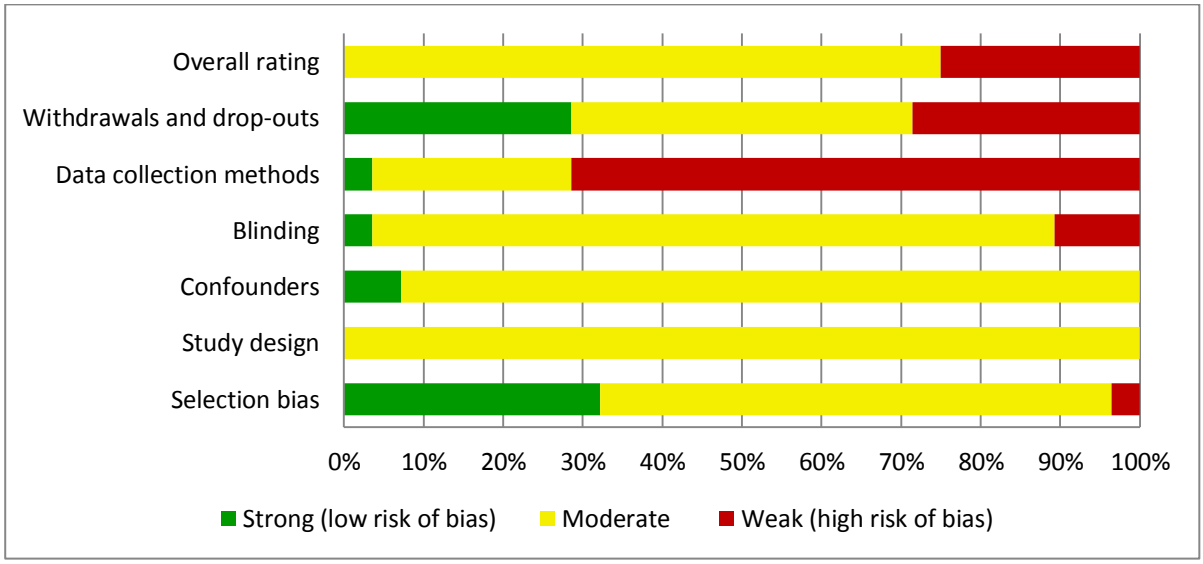
[1] The Gail model is a validated risk-assessment tool based on personal and family characteristics

Supplementary figure 1: Study flow chart





<u>Supplementary figure 2 legend</u>: Summary of risk of bias (%) for all included randomised controlled trials



<u>Supplementary figure 3 legend</u>: Summary of risk of bias (%) for all included prospective observational studies