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# BMJ Open

## The impact of cancer risk based interventions to people at population level risk: a systematic review and meta-analysis

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Manuscripts

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3 **The impact of cancer risk based interventions to people at population level risk:**  
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5 **a systematic review and meta-analysis**  
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## ABSTRACT

**Objective** To provide a comprehensive review of the impact of interventions incorporating cancer risk information targeted at the general adult population.

**Design** A systematic review and random effects meta-analysis

**Data sources** An electronic search of Medline, EMBASE, CINAHL and PsychINFO from 01/01/2000 to 01/12/2015.

**Inclusions criteria** Primary research papers evaluating interventions including provision of a personal estimate of future cancer risk based on two or more non-genetic variables to adults recruited from the general population.

**Results** We included 32 studies reporting on 21 outcomes. Risk-based interventions reduce perceived absolute risk (standardised difference in means (95%CI) between groups: -0.46 (-0.67 to -0.26)) and perceived comparative risk (-0.73 (-1.03 to -0.43)), increase accuracy of absolute risk but not comparative risk, and reduce cancer worry (-0.44 (-0.58 to -0.29)), while not affecting intention to attend or attendance at screening (RR 1.00 (0.97-1.03)). Few studies reported the impact on health behaviours.

**Conclusions** Whilst there is evidence that cancer risk-based interventions decrease perceived risk and worry, they have no effect on screening behaviour and there is no evidence of effectiveness on health behaviours. Further research is needed before cancer risk information is incorporated into routine practice for health promotion in the general population.

**Key words:** Cancer, risk, systematic review, intervention, prevention, communication

**Strengths and limitations of this study**

- This systematic review is the first comprehensive review of the impact of cancer risk-based interventions on individuals at population level risk for cancer.
- The use of a broad search strategy across multiple databases enabled us to identify 32 studies reporting the impact of cancer risk-based interventions on 21 outcomes.
- However, there was large heterogeneity across the studies and the different outcome measures included. This limited the pooling of results.

peer review only

## INTRODUCTION

In 2006 the National Cancer Institute recognised risk prediction models as an ‘area of extraordinary opportunity’<sup>1</sup>. Since then an increasing number of risk prediction models have been developed. Such models can facilitate a personalised approach to cancer prevention and treatment and a more equitable and cost-effective distribution of finite resources by targeting screening and prevention activities at those most likely to benefit. Furthermore, being able to estimate, communicate and monitor individual risk and demonstrate the impact of lifestyle change on future risk of cancer may complement wider collective approaches to shifting population distributions of behaviour, risk factors and cancer risk.

Research has shown that many individuals have incorrect perceptions of their risk of cancer<sup>2-4</sup> and that both over- and under-estimation are associated with maladaptive health behaviours<sup>5</sup>. Additionally, whilst up to 40% of all cancers are attributable to lifestyle factors<sup>6</sup>, only 3% of people are aware that being overweight can increase their risk of cancer and less than a third that physical activity could help reduce risk<sup>7-10</sup>, with one in seven people believing that lifetime risk of cancer is unmodifiable<sup>11</sup>. Providing individuals with estimates of their risk of cancer may improve accuracy of risk perception and motivate behaviour change at an individual level. It may also enable individuals to make more informed decisions around uptake of cancer screening programmes. This has led to an increasing number of interventions incorporating risk information being developed. All such interventions, however, have the potential to also cause harm both directly through reductions in psychological well-being and indirectly through false reassurance.

Information about risk of cardiovascular disease is now routinely offered to individuals, albeit with limited evidence of positive effects<sup>12</sup>. Understanding the impact of cancer risk based

1  
2 interventions, before they are introduced into routine practice, is therefore important. Previous  
3  
4 systematic reviews in this area have focused on randomised controlled trials in primary care<sup>13</sup>,  
5  
6 tailored information about cancer risk and screening<sup>14,15</sup>, or educational interventions for  
7  
8 people with cancer or at high risk of cancer<sup>16</sup>. We aimed to provide a comprehensive review of  
9  
10 the impact of provision of cancer risk-based interventions to the general adult population  
11  
12 across all settings.  
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## 16 17 **METHODS**

18  
19 We performed a systematic literature review following an a priori established study protocol  
20  
21 (available on request). Reporting followed the PRISMA statement<sup>17</sup>.  
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### 26 **Search strategy**

27  
28 We performed an electronic literature search of Medline, EMBASE, CINAHL and PsychINFO  
29  
30 from January 2000 until December 2015 with no language limits using a combination of  
31  
32 subject headings and free text incorporating ‘cancer’, ‘risk/risk factor/risk assessment’ and  
33  
34 ‘prediction/model/score/tool’ and outcomes including ‘perception’, ‘efficacy’, ‘anxiety’,  
35  
36 ‘worry’ and ‘denial’ (see Supplementary file 1 for the complete search strategies). We then  
37  
38 extended the search by manually screening the reference lists of all included papers.  
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42

### 43 **Study selection**

44  
45 We included studies if they were randomised controlled studies or pre-post intervention studies  
46  
47 published as a primary research paper in a peer-reviewed journal, included adults with no  
48  
49 previous history of cancer and included provision of a personal estimate of future cancer risk  
50  
51 based on two or more non-genetic variables to individuals. In order to focus on the provision of  
52  
53 cancer risk to the general population, we excluded studies which had recruited participants on  
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1  
2 the basis of a personal or family history of cancer or following referral to specialist cancer risk  
3 services. Vignette, observational and qualitative studies were also excluded along with  
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6 conference abstracts, editorials, commentaries and letters.  
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10  
11 Two reviewers (JUS and BS) screened the titles and abstracts to exclude papers that were  
12 clearly not relevant. A third reviewer (SG) independently assessed a random selection of 5% of  
13 the papers screened by each of the first reviewers. The full text was examined if a definite  
14 decision to exclude could not be made based on title and abstract alone. Two reviewers (JUS  
15 and BS) independently assessed all full-text papers. We discussed papers for which it was  
16 unclear whether or not the inclusion criteria were met at consensus meetings with a third  
17 reviewer (SG). Papers written in languages other than English were translated into English for  
18 assessment and subsequent data extraction.  
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### 30 **Data extraction**

31  
32 Two researchers (JUS+BS/KM) independently extracted data from studies included in the  
33 review using a standardized data abstraction form to reduce bias. The data extracted included:  
34  
35 (1) Study characteristics (cancer type, study design, study setting, duration of follow-up); (2)  
36 selection of participants (inclusion criteria, method of recruitment/randomisation); (3)  
37 participant characteristics (age, level of cancer risk, sample size); (4) the intervention (risk tool  
38 used, method and format of risk communication, additional information or follow-up  
39 provided), and (4) measured outcome(s). Reviewers were not blinded to publication details.  
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### 50 **Quality assessment**

51  
52 We conducted quality assessment at the same time as data extraction using a checklist based on  
53 the CASP guidelines<sup>18</sup> as an initial framework. Each study was then classified as high, medium  
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2 or low quality. No studies were excluded based on quality alone.  
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### 6 **Data synthesis and statistical analysis**

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8 For analysis, we grouped the measured outcomes into those relating to: 1) risk perception and  
9 understanding of risk estimate; 2) psychological well-being (e.g. worry, anxiety, depression);  
10 3) intention or motivation to change health-related behaviour; 4) intention to attend cancer  
11 screening; 5) change in health-related behaviour; and 6) cancer screening uptake. For  
12 continuous outcomes, the majority of the studies did not include sufficient data for us to  
13 express the effect of the intervention as a difference in the mean change from baseline between  
14 groups. We, therefore, present the standardised difference in mean values between groups at  
15 follow-up i.e. the difference in means expressed in standard deviation units. Where the  
16 standard deviation at follow-up was not reported, we used the standard deviation of the control  
17 group at baseline or the standard deviation from another study which measured the same  
18 outcome. For binary outcomes, such as screening attendance, we presented intervention effects  
19 as relative risk rather than odds ratios to avoid overestimating the risk<sup>19</sup>. Where possible we  
20 combined results from different studies using random effects meta-analysis but due to  
21 variations in study design and reporting we were only able to do this for a small number of  
22 outcomes. For outcomes with data from three or more studies, we estimated the heterogeneity  
23 between studies using the  $I^2$  statistic. We did not perform formal tests of heterogeneity for  
24 outcomes with data from less than three studies. All analyses were conducted using statistical  
25 software package STATA/SE version 12.  
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## 50 **RESULTS**

51 After duplicates were removed, the search identified 30,879 papers. Of these, 30,711 were  
52 excluded at title and abstract level and a further 142 after full-text assessment. After title and  
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2 abstract screening by the first reviewers (JUS and BS), no additional papers met the inclusion  
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4 criteria in the random 5% screened by the second reviewer (SG). The most common reasons  
5  
6 for exclusion at full-text level were that the papers did not include provision of a personal risk  
7  
8 estimate, were conference abstracts, recruited participants following referral to specialist  
9  
10 genetic services, or did not include any data on predefined outcomes (Figure 1). Six further  
11  
12 papers were identified through citation searching, giving 32 included studies in the analysis.  
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16  
17 A summary of the design and setting of those 32 studies is shown in Table 1. Further details of  
18  
19 the risk tool used to calculate the risk estimate provided to participants and the format of the  
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21 intervention(s) are given in Table 2. With the exception of two studies in the UK<sup>20,21</sup> and one in  
22  
23 the Netherlands<sup>22</sup>, all studies were conducted in the USA. Fifteen provided information about  
24  
25 risk of breast cancer, eight for colorectal cancer, three skin cancer, one each for lung and  
26  
27 cervical cancer and four for multiple cancers. Quality assessment for each of studies is  
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29 provided in Supplementary file 2. Eight were assessed as high or medium/high quality, 15 as  
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31 medium quality and 9 as medium/low or low quality.  
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37 Together, the 32 studies reported the impact of cancer risk-based interventions on 21 outcomes.  
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39 The overall findings for these along with the number of studies addressing each outcome are  
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41 summarised in Table 3.  
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### 45 **Risk perception and understanding of risk estimate**

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47 Perceived risk and accuracy of risk perception were the most frequent outcomes reported with  
48  
49 18 studies including a measure of one or both.  
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#### 54 *Perceived risk*

1  
2 Five randomised controlled trials (RCTs) measured either absolute risk perception (a numerical  
3 estimate of the individual's risk of developing cancer over a given time period) or comparative  
4 risk perception (an estimate of the individual's risk of developing cancer compared to others of  
5 the same age and sex) and included sufficient data for meta-analysis (Figure 2)<sup>23-28</sup>. In all five  
6 studies, on average, before provision of cancer risk information, participants overestimated  
7 both their absolute and comparative risk. The mean perceived absolute and comparative risk  
8 post intervention were significantly lower in those provided with personalised risk information  
9 than the control groups (standardised mean difference between groups: -0.46 (95%CI: -0.67 to  
10 -0.26,  $I^2 = 66%$ ) for perceived absolute risk and -0.73 (95%CI: -1.03 to -0.43,  $I^2 = 0%$ ) for  
11 perceived comparative risk). There were no clear differences according to format of the risk  
12 information or time between the intervention and outcome assessment.  
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28 We could not include a further seven studies in the meta-analysis. Two compared two  
29 intervention groups which received either absolute and comparative risk or comparative risk  
30 alone and found no significant changes in comparative risk perception from baseline to follow-  
31 up and no significant between-group differences<sup>21,29</sup>. An RCT by Dillard *et al.* only recruited  
32 women who overestimated their risk at baseline and compared effect of different styles of risk  
33 information. The overall estimate of lifetime risk across all groups decreased from 56.4% to  
34 28.4% post-intervention ( $n=72$ ) but the post-intervention levels remained significantly higher  
35 than the estimated risk (mean 11.2% difference)  $p<0.01$ <sup>30</sup>. By comparison Wang *et al.*<sup>31</sup>  
36 reported only on those who underestimated their risk at baseline. At the 6 month follow-up,  
37 perceptions about risk of colon cancer increased among a greater percentage of those in the  
38 intervention than in the control arm (17% vs 10%,  $p=0.05$ ), but not for breast cancer or ovarian  
39 cancer. Female college students who completed a self-assessment risk score also reported  
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2 increased perceived comparative susceptibility ( $p < 0.05$ ) post-intervention compared with those  
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4 who did not<sup>32</sup>.

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7  
8 Two RCTs by Lipkus *et al.*<sup>27,33</sup> tested the effect of providing absolute risk feedback alone,  
9  
10 comparative risk feedback alone or absolute plus comparative risk information. In one study,  
11  
12 women given absolute risk feedback alone had lower perceptions of their numerical 10-year  
13  
14 risks and comparative risk at follow up (16.8% (SD: 20.2) and 2.2 (SD: 0.8) respectively) than  
15  
16 women who also received comparative risk information (26.1% (SD: 23.4) and 2.8 (SD: 0.9),  
17  
18  $p < 0.05$ )<sup>33</sup>. In the other, perceptions of absolute risk did not vary significantly between groups  
19  
20 but those informed that they had more than the average number of risk factors compared with  
21  
22 others had higher mean comparative risk estimates than those in the control and in the lower  
23  
24 comparative risk feedback groups<sup>27</sup>.

### 25 26 27 28 29 30 *Accuracy of risk perception*

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32 Six RCTs reported accuracy of risk perception with and without provision of risk information.  
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34 It was possible to pool data from four studies that measured accuracy of absolute or  
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36 comparative risk perception after provision of either absolute risk information or absolute plus  
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38 comparative risk information<sup>34-37</sup>. Those who received risk estimates had more accurate  
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40 absolute risk estimates at follow-up (RR 5.54 (1.84 to 16.67)  $I^2=86.5%$ ), with no difference  
41  
42 between those provided with absolute risk alone or absolute plus comparative risk, while there  
43  
44 was no significant effect on comparative risk accuracy (RR 1.32 (0.82 to 2.13)  $I^2=78.2%$ ). A  
45  
46 further study which could not be pooled also showed an increase in the proportion who had  
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48 accurate absolute and comparative risk estimates from baseline to follow-up (75 (25%) to 147  
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50 (49%) for accurate absolute risk estimates and 88 (29%) to 138 (46%) for accurate comparative  
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52 risk)<sup>38</sup>. By contrast, one study showed no difference in the change in percentage of individuals  
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1  
2 overestimating their absolute risk (-2.7% in the control group ( $n=184$ ) compared to -5.8% in  
3  
4 the intervention group ( $n=183$ ),  $p=0.20$ )<sup>39</sup>.  
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8  
9 Two studies additionally compared the effect of alternative formats on risk accuracy. Emmons  
10  
11 *et al.* showed that those who were randomised to have the opportunity to see how adopting or  
12  
13 changing any of the risk factors would impact on their total risk profile had greater  
14  
15 improvement in accuracy for both comparative and absolute risk accuracy compared to those  
16  
17 who did not<sup>36</sup>. Lipkus *et al.* 2001a presented risk of breast cancer as either a point estimate on a  
18  
19 0-100% scale, as a range, or as a point estimate plus a range and showed no difference between  
20  
21 groups in the percentage of participants who were accurate immediately after receiving risk  
22  
23 information (point estimate 90.7%, point estimate plus range 97.7%, range 87.2-90.2%)<sup>40</sup>.  
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## 28 **Psychological well-being**

### 29 *Cancer worry*

30  
31  
32 Ten RCTs reported cancer worry. Three reported worry in the different groups before and after  
33  
34 the intervention using either the Lerman four item cancer worry scale<sup>41</sup>, which ranges from 4 to  
35  
36 16<sup>26,28</sup>, or a 10-point scale<sup>24</sup>, and were able to be summarised as the standardised difference in  
37  
38 mean worry between the intervention and control groups post intervention (Figure 3). The  
39  
40 meta-analysis shows an overall reduction in worry with a standardised difference in means of -  
41  
42 0.44 (95%CI: -0.58 to -0.29,  $I^2 = 0\%$ ).  
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48 Of the other seven RCTs which could not be pooled, six reported no significant intervention  
49  
50 effects and four reported no numerical results<sup>30,33,36,38</sup>. Three reported no change in the  
51  
52 proportion “*very concerned*” from baseline to follow up among controls (22.3% vs 22.0%,  
53  
54  $n=655$ ) compared with a non-significant decrease among intervention women (27.1% vs  
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1  
2 24.2%)<sup>34</sup>, and no significant differences in the change from pre- to post- intervention scores on  
3  
4 an adapted 3-item cancer worry scale with scores ranging from 3-12 (-0.17 for the intervention  
5  
6 group vs -0.24 for the control group,  $p=0.65$ )<sup>39</sup> or index of overall negative emotions about  
7  
8 getting colorectal cancer (CRC) on a scale from 3 to 15<sup>27</sup>.  
9

### 10 11 12 13 *Anxiety and depression*

14  
15 Two studies measured anxiety and depression. Holloway *et al.*<sup>20</sup> included five modified Likert  
16  
17 scales assessing screening-related anxiety and concerns alongside the Spielberger State  
18  
19 Anxiety Inventory (SSAI)<sup>42</sup>. Women in intervention practices were significantly less likely to  
20  
21 be “anxious about recent smear test” (OR: 0.81 (95%CI: 0.66 to 0.98)), “concerned about  
22  
23 chances of serious problems with smear test in the future” (OR: 0.70 (95%CI: 0.51 to 0.95)),  
24  
25 “fearful of cervical cancer” (OR: 0.66 (95%CI: 0.47 to 0.93)) and have a poor “perception of  
26  
27 gynaecological health” (OR: 0.43 (95%CI: 0.19 to 0.99)). They were also less likely to be  
28  
29 “concerned about smear result” but this was not statistically significant (OR: 0.75 (95%CI:  
30  
31 0.45 to 1.24)). After adjusting for clustering there was a non-statistically significant difference  
32  
33 between the groups in the SSAI (-1.6 (95%CI: -3.5 to 0.2),  $p=0.084$ ). The same study also  
34  
35 included 20 additional outcomes relating to general aspects of knowledge and psychosocial  
36  
37 wellbeing. No effect was seen for any of those relating to psychosocial wellbeing. The RCT by  
38  
39 Trevena *et al.*, also reported no significant difference in anxiety ( $p=0.56$ )<sup>43</sup>.  
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### 45 *Affect and health-related quality of life*

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47 Affect was measured using the Positive and Negative Affect Scale (PANAS)<sup>44</sup> in one RCT in  
48  
49 which the intervention group of female undergraduates received a risk feedback sheet whilst  
50  
51 the control group received no information<sup>30</sup>. No significant between-group differences were  
52  
53 observed. Health-related quality of life was measured in two RCTs<sup>28,45</sup> using the SF-36<sup>46</sup>. Both  
54  
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1  
2 reported a significant increase at follow-up in the intervention group compared with the control  
3  
4 group.  
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## 8 **Preferences and intentions for screening**

### 9 *Concordance between screening preferences and national recommendations*

10  
11 Two studies reported concordance between screening preferences and national  
12  
13 recommendations for cervical screening<sup>20</sup> and lung cancer<sup>47</sup>, both showed an increase in the  
14  
15 intervention group. In the cluster-randomised trial by Holloway *et al.*<sup>20</sup> participants in the  
16  
17 intervention group were significantly less likely to state a preference for the next screening  
18  
19 interval to be 12 months or less (OR: 0.51 (95%CI: 0.41-0.64)). In the pre/post study in the US  
20  
21 among a convenience sample of current or former smokers by Lau *et al.*<sup>47</sup> there was a  
22  
23 significant increase in those with preferences in line with the U.S. Preventive Services Task  
24  
25 Force recommendations from 25% to 59% (p<0.001), particularly amongst those ineligible for  
26  
27 screening where concordance increased from 14% to 53% (p<0.001).  
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### 35 *Decisional conflict*

36  
37 Two studies also reported a reduction in decisional conflict following risk information: the  
38  
39 before-and-after study by Lau *et al.*<sup>47</sup> showed a significant decrease from 46.3 (SD: 29.7) to  
40  
41 15.1 (SD: 25.8) assessed using the ten-item Decisional Conflict Scale; and Lipkus *et al.*<sup>27</sup>  
42  
43 showed that participants who received either absolute or absolute plus comparative risk had  
44  
45 significantly lower ambivalence than those in the control group.  
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### 50 *Intention to attend cancer screening*

51  
52 Eight studies included intentions to attend cancer screening, four for mammography and four  
53  
54 for CRC screening. Seven showed no effect of risk information. Bodurtha *et al.*<sup>48</sup> found no  
55  
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1  
2 significant differences between the groups at 18 months after adjusting for baseline intentions  
3 and recruitment site (adjusted OR: 0.97 (95%CI: 0.70 to 1.33)). Davis *et al.*<sup>39</sup> reported that the  
4 intervention group were no more likely at one month to report being in the maintenance stage  
5 (having had one mammogram in the past two years and two or more in the past four years and  
6 planning to get another on schedule) than the control group who received no intervention (67%  
7 in the intervention group compared to 68% in the control group). Lipkus *et al.*<sup>33</sup> reported the  
8 extent to which the risk estimate affected intentions to get a mammogram on a 5-point scale  
9 from “*much less likely*” to “*much more likely*”. Immediately after the risk information overall,  
10 2.5%, 67.8%, and 24.8% reported that the risk feedback lowered, did not affect, or increased  
11 their intentions to get a mammogram respectively, with no differences between the groups.  
12 Helmes *et al.*<sup>26</sup> reported changes in a single breast health intentions measure which included  
13 intention to have mammography, clinical breast examination, and breast self-examination and  
14 found no significant differences at baseline (p=0.23) or three month follow-up (p=0.46).  
15 Schroy *et al.*<sup>49</sup> showed no difference between groups on a five-point scale of how sure they  
16 were that they would schedule a CRC screening test (mean scores 4.3 (SD: 1.0) for both  
17 groups). Han *et al.*<sup>50</sup> also measured interest in CRC screening using a single five-point Likert  
18 response item. ANCOVA adjusting for sociodemographic factors only (age, race, sex) showed  
19 no significant change in interest in CRC screening following website use (change in interest =  
20 0.08 (95%CI: 0.07–0.23), p =0.31), and no significant effects of age, race, or sex. Trevena *et*  
21 *al.*<sup>43</sup> similarly reported no effect on intention to have CRC screening of a decision aid  
22 including baseline risk. The only study to show an effect was an RCT by Lipkus *et al.*<sup>27</sup>.  
23 Intention was measured on a seven-point Likert scale as the extent to which participants  
24 intended to complete a faecal occult blood test (FOBT) that would be given to them within the  
25 following month. The intentions reported by participants who received absolute risk (mean  
26 3.65, n=40) or absolute plus either low (mean 6.43, n=38) or high (mean 6.65, n=39)



1  
2 comparative risk information were statistically significantly higher ( $p<0.05$ ) than the control  
3  
4 group (mean 2.21,  $n=43$ ). The mean intention reported by the group which received the  
5  
6 comparative risk was also significantly higher than for the absolute risk only group.  
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### 10 **Attendance at screening**

11  
12 Twelve RCTs reported attendance at screening: six for mammography<sup>28,37,39,45,48,51</sup>; five for  
13  
14 colorectal cancer<sup>27,43,49,51,52</sup>; and one for cervical cancer<sup>20</sup>. All showed no effect of the risk-  
15  
16 based interventions and meta-analysis (Figure 4) confirmed this with a combined RR of 1.02  
17  
18 (95%CI: 0.98-1.03,  $I^2$ : 61.6%). A further cohort study which could not be included in those  
19  
20 pooled results reported the number of women adhering to the American Cancer Society  
21  
22 Guidelines for mammography before and after a risk based consultation with a pharmacist<sup>53</sup>.  
23  
24 No significant differences were seen after the intervention in any of the age groups or those at  
25  
26 higher risk.  
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### 32 **Intention to change health-related behaviours**

#### 33 *Smoking cessation*

34  
35 One cohort study<sup>54</sup> measured readiness to quit smoking over time after provision of  
36  
37 personalised cancer risk information. Including only those with data at all three time points, the  
38  
39 readiness to quit increased between baseline and one year ( $p<0.0001$ ) and two years ( $p<0.001$ ).  
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#### 45 *Intention to tan or protect skin*

46  
47 One RCT measured intention to tan on a six-item Likert-type scale and intention to protect skin  
48  
49 using a three-item scale<sup>32</sup>. Participants who completed a self-assessment risk score reported  
50  
51 significantly decreased intentions to use tanning beds (2.68,  $n=70$  compared to 3.19,  $n=71$ ,  
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1  
2 p<0.05). In contrast there were no significant differences in intentions to protect skin (2.38,  
3  
4 n=70 compared to 2.49, n=71, p>0.05).  
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## 8 **Change in health-related behaviours**

### 9 *Sun exposure and sun protection habits*

10  
11 Two RCTs<sup>21,55</sup> measured sun protection habits by survey completion at baseline and follow up.  
12  
13 Together these showed increases in overall sun protection habits with variable results for  
14  
15 individual aspects including wearing a sun hat, wearing a shirt, wearing sunglasses, use of sun  
16  
17 cream, number of sunburns, staying in the shade, and sun exposure during weekdays and  
18  
19 weekends.  
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### 23 *Tanning bed usage*

24  
25  
26 One RCT<sup>32</sup> measured tanning behaviour change and tanning bed usage following provision of  
27  
28 risk information. Participants who completed a self-assessment risk score reported lower rates  
29  
30 of tanning bed usage in the previous month at follow-up (2.18, n=70 compared to 3.76, n=71,  
31  
32 p<0.05) but no difference in change in tanning behaviour from pre- to post-intervention (-1.25,  
33  
34 n=70 compared to -2.08, n=71, p>0.05).  
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### 41 *Self/parent and clinical skin examination*

42  
43 Two RCTs measured rates of skin examination in adults<sup>21</sup> or parents and children<sup>55</sup>. Both  
44  
45 showed statistically significant increases among adults and parents receiving personalised risk  
46  
47 information (p<0.05) while the increase in parents examining their children was not significant  
48  
49 (p=0.06).  
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### 54 *Smoking*

1  
2 One cohort study<sup>54</sup> measured change in tobacco use and smoking status after providing  
3 personalised cancer risk information describing both modifiable and non-modifiable risk  
4 factors. Including only those with data at all three time points, the prevalence of current  
5 smokers increased from baseline to one year (5.7% to 6.7%,  $p<0.05$ ) but decreased from  
6 baseline to follow up at two years (5.7% to 5.3%,  $p<0.05$ ).  
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### 15 *Clinical breast examination and breast self-examination*

16  
17 Three RCTs<sup>28,45,48</sup> and one pre-post intervention study<sup>53</sup> measured rates of clinical breast  
18 examination and/or breast self-examination after risk information. In the RCT by Bodurtha *et*  
19 *al.*, no significant differences were seen between the intervention and control group for either  
20 frequency of clinical breast examination (crude rates: 91.4% vs 91.0%; adjusted OR: 1.00  
21 (95%CI: 0.60 to 1.66)) or breast self-examination (crude rates: 56.8% vs 57.6%; adjusted OR:  
22 0.95 (95%CI: 0.67 to 1.33)<sup>48</sup>. The other three studies showed significant increases: Giles *et al.*  
23 showed that adherence to the American Cancer Society guidelines for monthly breast self-  
24 examination increased from 31% to 56% ( $p<0.001$ ) for all women six months after the  
25 intervention and adherence to guidelines for clinical breast examination increased in women  
26 aged 40-49 years (81% to 97%,  $p<0.025$ )<sup>53</sup>; the two studies by Bowen *et al.*, found  
27 significantly ( $p<0.01$ ) greater increases in the proportion reporting performing breast self-  
28 examination in the intervention groups (35% to 52% and 36% to 62%) compared with controls  
29 (33% to 36% and 38% to 40%)<sup>28,45</sup>.  
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## 48 **DISCUSSION**

49 This systematic review is, to our knowledge, the first comprehensive review of the impact of  
50 cancer risk-based interventions on individuals at population level risk for cancer. The findings  
51 show that before receiving risk information, on average, people over-estimate their risk of  
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2 cancer – in some cases by a factor of three. Providing risk-based interventions reduces  
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4 perceived risk, increases accuracy of absolute risk but not comparative risk, and reduces cancer  
5  
6 worry, whilst not affecting intention to attend or attendance at screening. Risk-based  
7  
8 interventions also increase self-report sun protection habits and skin examination and may  
9  
10 decrease smoking but there is a notable absence of studies assessing the impact on diet,  
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12 physical activity or alcohol consumption and none including objective measures of behaviour.  
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16  
17 The finding that people tend to overestimate their risk and that provision of risk-based  
18  
19 information on average reduces risk perception has been reported for other diseases, including  
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21 diabetes<sup>56</sup>, coronary heart disease<sup>57</sup> and cardiovascular disease<sup>12</sup>. Whilst this reduction in  
22  
23 perceived risk may reduce maladaptive behaviours such as avoidance or denial<sup>5</sup>, there is also  
24  
25 the possibility that, instead of promoting healthy lifestyles, provision of disease risk  
26  
27 information may provide false reassurance and encourage the adoption of unhealthy  
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29 behaviours.  
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35 However, risk perception is not as simple as recalling a number or comparative estimate and  
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37 conceptual problems in understanding risk information are well known<sup>58</sup>. Qualitative studies  
38  
39 have also shown that an individual's risk perception is based on a complex integration of  
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41 cognitive and social biases<sup>59</sup> arising from personal or lay theories of disease and risk<sup>24,33,60</sup> and  
42  
43 past experiences, expectations and beliefs<sup>61</sup>. This may in part explain our finding that risk-  
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45 based inventions improve accuracy of absolute risk perception but not comparative risk. By its  
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47 very nature comparative risk is a more emotive construct and one which may be more prone to  
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49 cognitive and social biases and in turn more resistant to change. For the same reasons,  
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51 however, comparative risk may play a more important role in influencing decisions concerning  
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53 health behaviours.  
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4 Our finding that risk-based interventions had no effect on intention to attend or attendance at  
5 screening is consistent with a previous Cochrane review in which personalised risk  
6 communication had little effect on the uptake of screening tests (fixed-effect OR 0.95 (95% CI  
7 0.78 to 1.15))<sup>15</sup>. However, as in that review, there was evidence of decreased decisional-  
8 conflict and increased concordance between screening preferences and recommendations. This  
9 suggests that providing individuals with risk-based information may contribute to their  
10 decision to take up screening or not but is unlikely to influence overall rates of screening.  
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21 The main strengths of this review are the systematic search of multiple electronic databases and  
22 the broad inclusion criteria. Together these allowed us to include studies that assess the impact  
23 of cancer risk-based interventions on multiple outcomes. We have, therefore, been able to  
24 provide the first comprehensive overview of the impact of cancer risk-based intervention on  
25 individuals at population level risk. This approach, however, has its limitations. Firstly, there  
26 was large heterogeneity between the studies and in many the intervention consisted of  
27 provision of a risk score plus a range of additional information, either written or delivered in  
28 person or in groups. Separating the effect of the risk information alone from these additional  
29 elements of the interventions was therefore not possible. Secondly, although we have included  
30 21 outcomes reported across the included studies, as a result of this number of outcomes, we  
31 were not able to assess and report all the interactions and moderators and mediators. Instead we  
32 have presented the overall effects that can be expected if risk information were to be provided  
33 to those at population level risk. Thirdly, as many of the included studies did not include  
34 sufficient data for us to express the results of continuous measures as the difference in the  
35 standardised mean change between groups, we have only been able to present the difference in  
36 mean values at follow-up. Finally, the heterogeneity remained high for several of the outcomes.  
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2 This likely reflects underlying variations in the design of the included studies and the different  
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4 components included within the interventions but we feel our pooling of the data is justified in  
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6 order to provide overall estimates reflecting the inherent variations in intervention delivery  
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8 outside trial settings.  
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13 In addition to these specific limitations of our review, the findings also suggest a number of  
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15 areas for future research. In particular, the absence of studies assessing the impact on diet,  
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17 physical activity and alcohol consumption demonstrate the need for trials incorporating change  
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19 in these behaviours, preferably measured objectively. Only with such data will we be able to  
20  
21 assess whether the observed impacts on risk perception and accuracy translate into meaningful  
22  
23 changes in risk factors and whether such individualised approaches have a place alongside  
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25 population-wide prevention strategies.  
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31 Overall, this review demonstrates that whilst a large number of cancer risk prediction models  
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33 exist and their incorporation into interventions does decrease perceived risk and worry and  
34  
35 increase absolute risk accuracy, there is evidence that they have a minimal effect on screening  
36  
37 behaviour and no evidence of their effectiveness on health behaviours. Further research is  
38  
39 therefore needed before cancer risk information is incorporated into routine practice for those  
40  
41 at population level risk of cancer.  
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51

## 52 **Contributors**

1  
2 JUS developed the protocol, completed the search, screened articles for inclusion, extracted  
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4 the protocol, screened articles for inclusion, extracted data, interpreted the results and critically  
5 revised the manuscript. SS synthesized the findings and critically revised the manuscript. KM  
6 extracted data, interpreted the results and critically revised the manuscript. SJG developed the  
7 protocol, screened articles for inclusion, interpreted the results and critically revised the  
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40 All data are available from the reports or authors of the primary research. No additional data is  
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### 48 **Competing Interests**

49 All authors have completed the Unified Competing Interest form at  
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18  
19 integrity of the data and the accuracy of the data analysis  
20

21 The corresponding author affirms that the manuscript is an honest, accurate, and transparent  
22  
23 account of the study being reported; that no important aspects of the study have been omitted;  
24  
25 and that any discrepancies from the study as planned (and, if relevant, registered) have been  
26  
27 explained.  
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## 29 30 **FIGURE LEGENDS**

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34 Figure 1. PRISMA flow diagram

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36  
37 Figure 2. Standardised difference in mean perceived absolute and comparative between groups  
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39 post intervention. AR – absolute risk; CR – comparative risk  
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42 Figure 3. Standardised difference in mean worry between groups post intervention. AR –  
43  
44 absolute risk; CR – comparative risk  
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46  
47 Figure 4. Relative risk for adherence to recommended screening post intervention. CRC –  
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49 colorectal cancer; FOBT – faecal occult blood test; AR – absolute risk; CR – comparative risk  
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**Table 1.** Details of the design, setting and key outcomes of the included studies

Author, year	Cancer site(s)	Design	Follow-up	Setting and participants	Risk level / co-morbidities	Outcome(s)	Quality *
Bodurtha 2009	Breast	RCT	18 months	899 women with no history of breast cancer recruited from waiting rooms of four women's health clinics	Not given	Mammography, clinical breast examinations, breast self-examination, mammography intentions	M-H
Bowen 2006	Breast	RCT	6 and 24 months	150 sexual minority women recruited via public advertisements	Mean Gail lifetime risk 12%	Perceived risk, cancer worry, mental health, breast self-examination, breast cancer screening	H
Bowen 2010	Breast	RCT	12 months	1,366 women recruited via telephone with no previous diagnosis of breast cancer	Mean Gail lifetime risk 12%	Quality of life, breast self-examination, mammography	
Davis, 2004	Breast	RCT	1 month	392 women with no history cancer calling the Cancer Information Service	27% 2-6% lifetime risk; 32% 6-9% lifetime risk; 41% 9-46% lifetime risk	Adherence to breast cancer screening, intention for breast cancer screening, risk perception, cancer worry	M
Dillard, 2006a	Breast	RCT	0, 2 weeks	Convenience sample of 72 female undergraduates with no first degree relatives with breast cancer	Not given	Mood, comparative risk estimates, percentage risk estimates for other women, worry, beliefs about the accuracy of the feedback, seriousness ratings concerning breast cancer	L-M
Dillard, 2006b	Breast	RCT	0, 2 weeks	Convenience sample of 62 female undergraduates with no first degree relatives with breast cancer	Not given	Perceived risk	L-M
Emmons, 2004	Colorectal	RCT	0	353 patients with no history of cancer scheduled for routine or non-urgent health care visits to two primary care practices	Mean 20 year risk 9.96 per 1,000	Accuracy of risk perception, cancer worry	M-H
Giles 2001	Breast	Cohort	6 months	140 members of general public attending one of six community pharmacies	15% ≥ 1.7 lifetime risk	Breast self-examination, clinical breast examination, mammography screening	M
Glanz 2013	Skin	RCT	16 weeks	Convenience sample of 1047 parents not currently being treated for skin cancer recruited through schools and community centres	38% high risk	Sun protection habits, sun exposure, skin examination by parents	M
Glazebrook 2006	Skin	Cluster RCT	6 months	589 recruited from 10 primary care practices from a convenience sample of appointments	Not given	Sun protection habits, perceived risk	M
Greene 2003	Skin	RCT	3-4 weeks	141 undergraduates at one university	Not given	Perceived risk, intention to tan, actual tan bed usage	L-M
Han, 2015	Colon	Cohort	0	578 members of general public accessing freely	0.8-22% lifetime	Interest in getting tested or screened for	M

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2					accessible website "Are you at risk for colon	risk	colon cancer	
3					cancer"			
4	Helmes,	Breast	RCT	3	Random sample of 340 members of state	Mean 9.5% (3.2)	Risk perception, cancer worry, intention to	M
5	2006			months	healthcare system with no history of	lifetime risk	have mammogram and clinical breast	
6					breast/ovarian cancer or testing for cancer risk		examination, intention to do breast self-	
7							examination, interest in genetic testing	
8	Holloway,	Cervical	RCT	0, 4	1890 women attending routine cervical smear	78-80% very low	Preference for future screening interval,	M-H
9	2003			years	test at one of 29 GP practices	risk; 20-22% low	screening related anxiety, screening related	
10						risk	mental health, actual screening behaviour, 21	
11							short-term outcome measures relating to	
12							knowledge and psychosocial wellbeing	
13	Kaplan	Breast	RCT	1 week	1235 patients scheduled for routine or non-	75% average risk	Patient-physician discussion and	L-M
14	2014			and 6	urgent health care visits to two primary care		documentation of breast cancer risk	
15				months	practices with no history of breast cancer			
16	Lau 2015	Lung	Cohort	0	Convenience sample of 60 current or former	Mean 6-year risk	Knowledge of cancer risk factors and lung	L-M
17					smokers with no history of lung cancer and who	0.012%	cancer screening, decisional conflict,	
18					had not have a chest CT in the previous year		concordance	
19	Lipkus	Colorectal	RCT	0	160 members of general public with no history	Not given	Absolute and comparative CRC risk, worry,	M
20	2006				of CRC or screening for CRC recruited through		defensive reactions, ambivalence, intention to	
21					newspaper advertisements		screen using a FOBT, actual FOBT screening	
22							rates	
23	Lipkus,	Breast	2x2	0, 6-8	169 members of general public recruited through	Mean lifetime risk	Perception of risk	L
24	2001a		design	months	newspaper advertisements	7.78% (SD 1.13)		
25	Lipkus,	Breast	RCT	0	121 members of general public recruited through	Mean 10 year risk	Perception of risk, negative affect related to	M
26	2001b				newspaper advertisements	2.65% (SD 1.13)	getting breast cancer, mammography	
27							screening and intentions	
28	Lipkus,	Breast	RCT	0	301 members of general public recruited through	Mean lifetime risk	Perception of risk, accuracy of risk, breast	L
29	2005				newspaper advertisements	8.5%	cancer worry	
30						(range 1.2 to		
31						30.5)		
32	Livaudais-	Breast	RCT	1 week	1235 women with scheduled appointments at an	25% high risk	Perception of risk, breast cancer concern	H
33	Toman,				academic medical center or hospital with no			
34	2015				history of breast cancer			
35	McCaul,	Breast	2x2	0, 1-2	59 female undergraduates with no first-degree	Mean lifetime risk	Perception of risk, accuracy of risk, breast	L
36	2003		design	weeks	relatives with breast cancer at one university	11.5%	cancer worry	
37	Quillin,	Breast	RCT	1 month	299 women with no history of breast cancer	Mean lifetime risk	Perception of risk, risk accuracy	M
38	2004				attending outpatient mammography clinic	11.1% (SD 5.14)		



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2	Rimer	Breast	RCT	1 and 2	752 women aged 40-44 and 50-54 enrolled in a	Mean 10 year risk	Risk accuracy, mammography	M	
3	2002			years	personal care plan	2.7%			
4	Rubenstein	Breast, ovarian, colon	RCT	6	3786 patients from primary care clinics with no	34% moderate or	CRC screening, mammography	M	
5	2011			months	history of colon, breast or ovaraian cancer	strong risk of $\geq 1$			
6					invited by mail following record review	of the cancers			
7	Schnoll,	Lung, breast, colorectal	Cohort	1 and 2	6378 employees and their spouses from six	Not given	Smoking status, readiness to quit smoking	M-H	
8	2005	, ovarian, skin, prostate		years	worksites				
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13	Schroy,	Colorectal	RCT	0	666 patients due for bowel screening identified	Average	Knowledge, preferences, satisfaction with the	M-H	
14	2011				from monthly audits of one hospital's electronic		decision-making process, screening		
15					medical record		intentions, and test concordance		
16	Schroy,	Colorectal	RCT	0, 1, 3, 6	825 patients due for bowel screening identified	Average	Completion of a CRC screening test	H	
17	2012			and 12	from monthly audits of one hospital's electronic				
18				months	medical record				
19	Sequist	Colorectal	RCT	1 and 4	1,103 patients from 14 ambulatory health centres	Average	CRC screening	M	
20	2012			months	who were overdue for colorectal cancer				
21					screening				
22	Timmerma	Colon, lung	RCT	0	612 members of general public with no history	4.6% reported a	Risk accuracy	M	
23	ns 2012				of cancer	history of cancer			
24	Trevena	Colorectal	RCT	1 month	314 patients recruited from 6 primary care	Not given	Anxiety, screening intentions, CRC screening	M	
25	2008				practices without a history of colorectal cancer				
26	Wang,	Colon, breast, ovarian	RCT	6	3786 patients from primary care clinics with no	82% moderate or	Perception of risk	M	
27	2012			months	history of colon, breast or ovarian cancer invited	strong risk for $\geq 1$			
28					by mail following record review	of the 6			
29						conditions			
30	Weinstein,	Colon	2x2	0	353 patients with no history of cancer with	Below-average	Recall of risk communication, risk accuracy	L-M	
31	2004		design		scheduled routine or non-urgent health care				
32					visits at two primary care practices				

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34 RCT – randomised controlled trial; CRC – colorectal cancer; CT computerised tomography; FOBT – faecal occult blood test  
35 \* L – low, M – medium, H - high  
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**Table 2.** Details of the risk-based interventions in each of the included studies

Author, year	Risk tool	Intervention group(s)	Comparison (where applicable)	Format of risk
Bodurtha 2009	Gail model (5 year and lifetime)	Information sheets with risk level and handouts addressing traditional constructs of Health Belief Model including barriers to mammography, breast cancer seriousness, individual risk for breast cancer, and benefits of yearly mammography	General information about breast cancer prevention practices, including mammography	Usual (<15%), Moderate (15-30%) or Strong (>30%)
Bowen 2006	Gail model (5 year, 10 year and at age 79)	Four weekly 2-hour sessions led by a health counsellor focusing on risk assessment and education, screening, stress management and social support	Delayed intervention	No details given
Bowen 2010	Gail model (lifetime)	Information sheets with general information on breast cancer risk and personalised risk information plus telephone counselling and offer for more intensive group or genetic counselling	Delayed intervention	Bar graph of absolute lifetime risk along with age-appropriate estimates for the "average risk" woman
Davis, 2004	BRCA tool (updated version of Gail model) (lifetime)	10min brief intervention designed to increase accuracy of perceived risk including results of risk assessment and screening recommendations tailored to participant's stage of adoption of mammography and follow up written information	No intervention	Verbal over the telephone. No additional details given.
Dillard, 2006a	Gail model (5 year and lifetime)	Risk feedback sheet following completion of risk assessment questions plus kindness questionnaire or study calendar +/- additional questions about risk factors	No intervention	Absolute risk estimate as % and comparative estimate ranging from 'much lower' to 'much higher' along with a visual scale with risk estimate represented by a mark on the scale
Dillard, 2006b	Gail model (5 year and lifetime)	Risk feedback sheet including information on two other women and their risk factors as downward social comparison condition	Risk feedback sheet	Absolute risk estimate as % and comparative estimate ranging from 'much lower' to 'much higher' along with a visual scale with risk estimate represented by a mark on the scale +/- downward social comparison condition
Emmons, 2004	Harvard cancer risk model (20 year)	1) Absolute risk with active impact; 2) Absolute risk without active impact; 3) Absolute and relative risk with active impact; 4) Absolute and relative risk without active impact	Passive risk communication but no absolute or relative risk estimates	Absolute risk over 20 years +/- relative risk plus absolute risk +/- option to manipulate their risk factor profiles to see impact of changing risk factors on a visual scale using an interactive computer-based tool
Giles 2001	Gail model (5 year and lifetime)	Pharmacist consultation and written explanation of individual risk factors with 5 year probability, lifetime probability, comparison with someone of the same age with	Not applicable	Bar chart of absolute risk as a percentage for 5 year and lifetime risk alongside risk of a woman of the same age and race with no

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2			no additional risk factors along with encouragement to		additional risk factors
3			follow guidelines for breast self-examination and		
4			mammograms		
5	Glanz 2013	Children's BRAT	Three mailings with personalised risk feedback, interactive	Single mailing of	No details given
6			skin cancer education materials, a family fun guide and	standardised skin cancer	
7			suggestions for overcoming barriers and reminders to engage	information	
8			in preventive practices		
9	Glazebrooke	No details given	Self-directed computer program including sections on skin	Not applicable	Comparative risk
10	2006		protection, how to detect melanoma, dangers of sun		
11			exposure, how to check skin, how to reduce risk and		
12			individualized feedback of risk		
13	Greene 2003	Relative risk	Self-assessment of risk alongside generic messages about	Generic messages about	Numerical scale from 1-36
14		adapted from "ADD	tanning, tanning beds and sun exposure	tanning, tanning beds and	
15		Wants to Convert"		sun exposure	
16					
17	Han, 2015	CCRAT (NCI	Individual's estimated CRC risk as well as age- and sex-	Not applicable	Absolute 5-year, 10-year and lifetime risk on
18		Colorectal Cancer	matched population average CRC risk		visual scale from 0-100% and pictogram
19		Risk Assessment			with 100 people for individual and age- and
20		Tool) (5, 10 year			sex-matched population average
21		and lifetime)			
22	Helmes,	Gail model	Face-to-face or telephone intervention consisting of 8 items:	No intervention	Bar charts of absolute % risk with numerical
23	2006	(lifetime)	1) a personal risk sheet ; 2) a personal computer-drawn		% alongside for the individual, an average-
24			pedigree; 3) a 23 page participant booklet; 4) Breast self-		risk woman, and a high-risk woman
25			examination brochure; 5) Pap smear and mammography		
26			brochure; 6) BSE shower card; 7) pictures of chromosomes		
27			and gene mutations; 8) a list of community resources for		
28			breast cancer		
29	Holloway,	Wilkinson score	Brief 10 minute counselling session integrated with smear	Normal care	Comparative and absolute risk in pictures
30	2003		test appointment including relative and absolute risks and		and numbers
31			then negotiation of appropriate screening intervals		
32	Kaplan 2014	Referral Screening	Breast cancer risk assessment by tablet computer at the clinic	Breast cancer risk	High risk or average risk
33		Tool; Gail Model;	that generated individually tailored printouts for patients and	assessment via telephone	
34		and Breast Cancer	their physicians		
35		Surveillance			
36		Consortium model			
37		(5 year)			
38	Lau 2015	PLCom2012 model	Web-based decision aid which computed baseline lung	Not applicable	Absolute risk as % and on visual scale plus

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2		(6 year)	cancer risk and an individual's chance of benefiting from,		pictogram of 100 people showing benefits of
3			and risk of being harmed by, screening		lung cancer screening and description of
4					harms and benefits with numbers for each
5	Lipkus 2006	Not given	Written information about CRC, CRC screening methods	Written information about	Narrative comparative risk
6			and CRC risk factors plus either 1) tailored CRC risk factor	CRC, CRC screening	
7			information or 2) tailored CRC risk factor information plus	methods, and CRC risk	
8			information on whether their total number of CRC risk	factors	
9			factors was greater or not than average		
10	Lipkus,	Gail model	1-2 page handout describing the Gail Model plus either 1) a	No information	As a percentage in a pie chart
11	2001a	(lifetime)	point estimate of their risk; 2) a risk range derived from the		
12			95% confidence intervals; 3) a point estimate of their risk		
13			plus a risk range derived from the 95% confidence intervals		
14	Lipkus,	Gail model (10	1 page handout describing the Gail model plus absolute risk	As for intervention group	Absolute risk +/- risk of a woman at the
15	2001b	year)	alone	plus how their risk compared	lowest level of risk as percentages in a pie
16				to a woman of their age and	chart
17				race at the lowest level of	
18				risk	
19	Lipkus, 2005	Gail model	In three groups, women obtained information about their	No information	Numerical percentages either 1) "point
20		(lifetime)	absolute risk only, in one of three formats. Three additional		estimate condition" - single best point
21			groups received their absolute risk in one of the three		estimate of their risk as a percentage; 2)
22			formats along with information about the risk of another		"range condition" - upper and lower
23			woman the same age and race as the participant with no		bounds of risk as percentages; 3) "point
24			other risk factors		estimate and range"
25	Livaudais-	Referral Screening	Individually-tailored print-outs for patients and their	No information	Absolute risk as a percentage and relative
26	Toman, 2015	Tool; Gail Model;	physicians (one page in length) including specific risk		risk (higher/lower)
27		and Breast Cancer	reduction recommendations.		
28		Surveillance			
29		Consortium model			
30		(5 year)			
31	McCaul,	Gail model (5 year	Printed feedback on two sheets including either absolute risk	No information	Absolute risk as a percentage and mark on
32	2003	and lifetime)	information, relative risk information, or both		two scales ranging from 0% to 100%.
33					Comparative risk as a label (e.g., 'Same')
34					and a mark on a scale ranging from 'Much
35					lower' to 'Much higher,' with seven labels
36					including a centre label of 'About the Same'
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Quillin, 2004	Gail model (5 year and lifetime)	Risk assessment with genetic counsellor then one-page summary including breast health messages that were appropriate for their calculated risk, including recommendations for screening, available genetic counselling, and contact information for psychosocial support	No information	Percentage risk alongside qualitative interpretation ("low", "moderate", high") and whether it is higher/lower than the average women's risk
Rimer 2002	Gail model (10 year and lifetime)	Tailored print booklet and brief tailored newspaper plus personalized risk	Usual care (postcard reminder)	Absolute risk as a percentage
Rubenstein 2011	Family Healthware tool	Written personalized risk assessment and tailored prevention messages	Written generalized prevention messages	Qualitative risk - weak, moderate or strong familial risk
Schnoll, 2005	Not given	A personalized risk-feedback letter, which listed modifiable and non-modifiable cancer risk factors, calculated risk, and information about specialized risk-reduction programs.	Not applicable	Qualitative risk - above average or average
Schroy, 2011	Harvard cancer risk model (10 year)	Interactive 20-30 min computer-based decision aid plus personalized risk assessment	Interactive 20-30 min computer-based decision aid alone	Thermograph, indicating where the participant is along with a description e.g. your risk is below average
Schroy, 2012	Harvard cancer risk model (10 year)	Interactive 20-30 min computer-based decision aid plus personalized risk assessment followed immediately by a meeting with their providers to discuss screening and identify a preferred screening strategy. Providers received written notification hand-delivered by all the patients acknowledging that they were participating in the "CRC decision aid study" at the time of the visit to ensure that screening was discussed	As for intervention but without personalized risk assessment	Qualitative framing ("very much below average risk" to "very much above average risk") with accompanying suggestions for behaviour modifications that might reduce risk, including a strong recommendation for screening, regardless of risk
Sequist 2011	Harvard cancer risk model (10 year)	Personalized electronic message highlighting their overdue screening status and providing a link to a web-based tool to assess their risk	No contact	Comparative risk on 7-point ordinal scale from very-much below average to very-much above average and in interactive graphical format
Timmermans 2012	Shortened KWF Kanker Risico Test (5 year)	Participants were randomized to one of 12 experimental groups who received a combination of: 1) Average population risk (no quantitative risk information provided/only the number/number + graphic illustration); 2) the calculated personal risk (no quantitative information /numbers); and 3) the relative risk reduction after changing lifestyle (or no quantification of risk reduction)	Standard version of the KWF-KRT	12 different formats including numbers, graphical illustrations (emoticons and bar charts) of average population risk, personal risk and relative risk reduction

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2	Trevena	No details given	20 page booklet including personalized risk, absolute	3 page booklet with	Words and 1000-face diagrams
3	2008		reduction in colorectal cancer mortality with screening over	information and	
4			the next 10 years, probability of test outcomes from	recommendations about	
5			screening and information about how to get screened.	screening	
6	Wang, 2012	Family Healthware	Written personalized prevention messages delivered via	Standard print messages	Qualitative risk - weak, moderate or strong
7		tool	mail, e-mail, or in person tailored to familial risk for each of	about screening and lifestyle	familial risk
8			the six conditions alongside a family tree and information	choices via mail, e-mail, or	
9			about the characteristics in one's family history that put the	in-person	
10			person at increased risk (if applicable)		
11	Weinstein,	Harvard cancer risk	Absolute or relative risk electronically +/- the opportunity to	Feedback on which of their	Absolute risk - numerical estimate in units
12	2004	model (20 year)	manipulate the risk along with details of the risk factors that	behaviours and non-	of cases per thousand people like them
13			comprised their risk and recommendations for what they	modifiable attributes	alongside an oval window with the risk
14			should change to reduce their risk	lowered and which increased	marked on a horizontal hairline.
15				their risk and advice on steps	Comparative risk was expressed in terms of
16				they could take to lower their	one of seven categories: "very much below
17				risk	average", "much below average," "below
18					average," "average", "above average,"
19					"much above average," and "very much
20					above average" alongside an oval window
21					with the risk marked on a horizontal hairline
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23	CRC – colorectal cancer				
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CRC – colorectal cancer

**Table 3.** Summary of impact of provision of personalised cancer risk on measured outcomes

	<b>Decrease</b>	<b>No change</b>	<b>Increase</b>
Risk perception	Perceived risk ( <i>n</i> =12)		Absolute risk accuracy ( <i>n</i> =5) -----Comparative risk accuracy ( <i>n</i> =3) -----
Psychological outcomes	Worry ( <i>n</i> =10) -----Anxiety ( <i>n</i> =2)-----	Depression ( <i>n</i> =2) Affect ( <i>n</i> =1)	Quality of life ( <i>n</i> =2)
Health behaviour	Intention to use tanning beds ( <i>n</i> =1) Smoking ( <i>n</i> =1)	Intention to protect skin( <i>n</i> =1) Clinical breast examination ( <i>n</i> =2) Use of tanning beds ( <i>n</i> =1)	Readiness to quit smoking( <i>n</i> =1) Sun protection habits ( <i>n</i> =2) Skin examination ( <i>n</i> =2) Breast self-examination ( <i>n</i> =4)
Screening	Decisional conflict around screening decisions ( <i>n</i> =2)	Intention to attend screening ( <i>n</i> =8) Attendance at screening ( <i>n</i> =13)	Concordance between screening preferences and recommendations ( <i>n</i> =2)

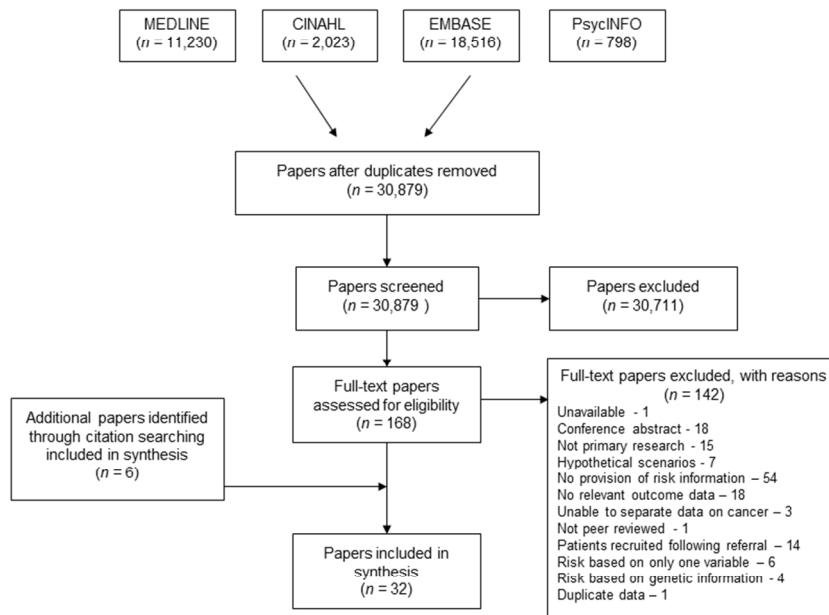


Figure 1. PRISMA flow diagram

254x190mm (96 x 96 DPI)



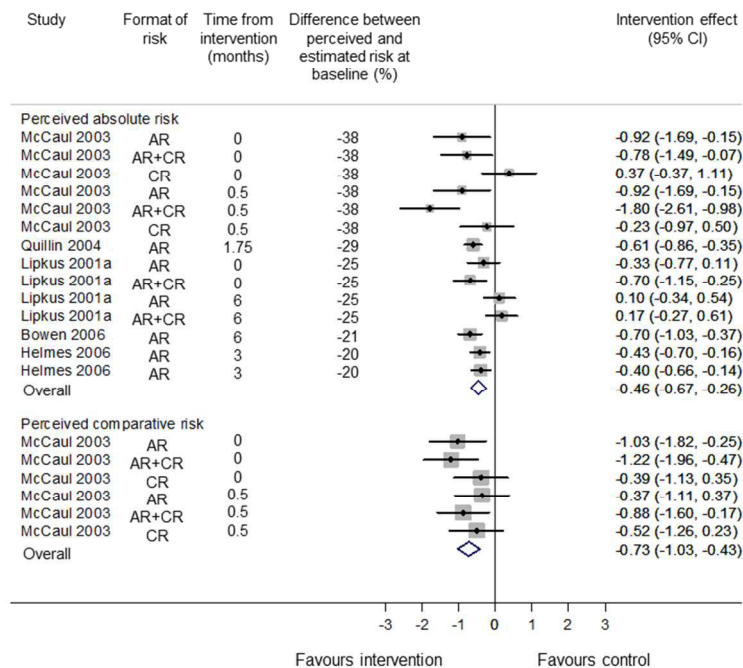


Figure 2. Standardised difference in mean perceived absolute and comparative between groups post intervention. AR – absolute risk; CR – comparative risk

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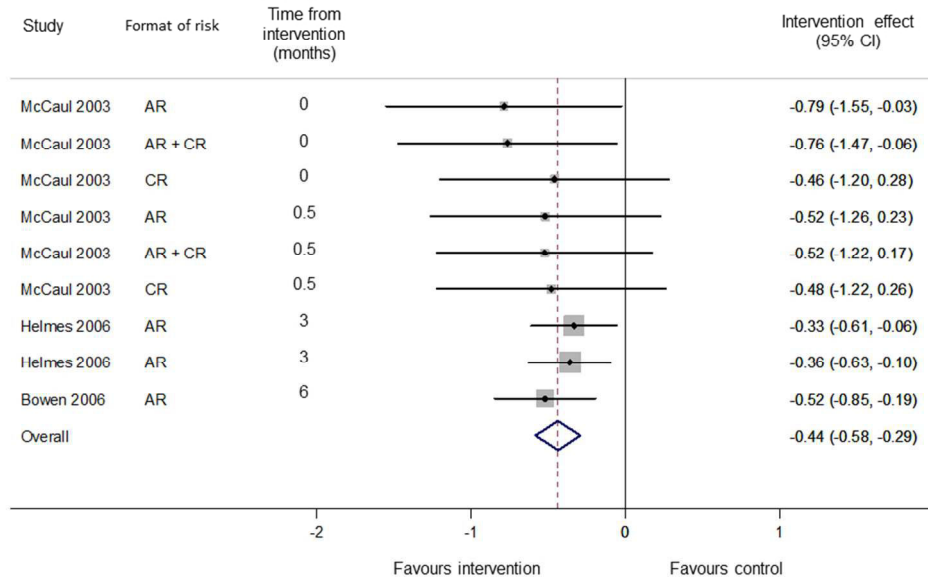


Figure 3. Standardised difference in mean worry between groups post intervention. AR – absolute risk; CR – comparative risk

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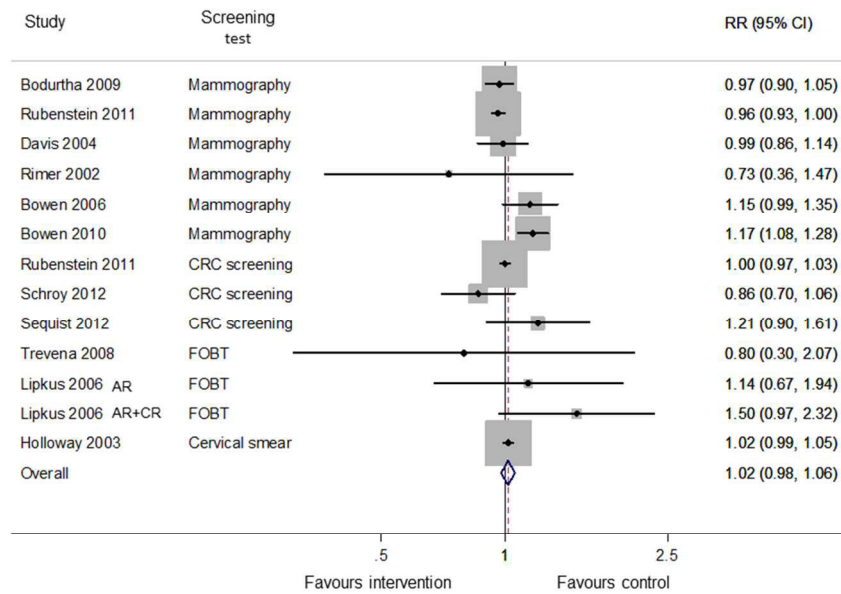


Figure 4. Relative risk for adherence to recommended screening post intervention. CRC – colorectal cancer; FOBT – faecal occult blood test; AR – absolute risk; CR – comparative risk

254x190mm (96 x 96 DPI)

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## Supplementary file 1 – Complete search strategy

### *Medline and Cinahl*

S28 S26 NOT S27  
S27 review  
S26 S24 AND S25  
S25 S13 NOT S15  
S24 S14 OR S16 OR S17 OR S21 OR S22 OR S23  
S23 (behaviour OR behavior) AND health  
S22 (MH "Health Behavior+") OR (MH "Risk Reduction Behavior+")  
S21 S18 OR S20  
S20 S19 AND S1  
S19 screen\* AND uptake OR attendance OR intention OR adherence  
S18 (MM "Early Detection of Cancer/UT")  
S17 anxiety\* OR worry\* OR denial\* OR hopelessness\* OR avoidance\*  
S16 efficacy OR effectiv\*  
S15 PT review OR PT letter OR PT comment OR PT editorial  
S14 percep\* OR perceive\* OR understand\* OR understood\* OR accura\* OR comprehen\*  
S13 S9 NOT S12  
S12 S10 OR S11  
S11 (MH "Prognosis+")  
S10 prognos\* OR treatment\* OR surgery\*  
S9 S1 AND S8  
S8 S6 OR S7  
S7 (MH "Risk Assessment+")  
S6 S4 AND S5  
S5 score\* OR model\* OR predict\* OR tool\*  
S4 S2 OR S3  
S3 (MH "Risk+")  
S2 risk\*  
S1 "cancer" OR (MH "Neoplasms+")

### *Embase*

1 cancer.mp. or exp neoplasm/  
2 exp risk/ or risk\*.mp.  
3 (score\* or model\* or predict\* or tool\*).mp. [mp=title, abstract, heading word, drug  
4 trade name, original title, device manufacturer, drug manufacturer, device trade name,  
5 keyword]  
6 2 and 3  
7 exp risk assessment/  
8 4 or 5  
9 1 and 6  
10 (percep\* or perceive\* or understand\* or understood\* or accura\* or comprehen\*).mp.  
11 [mp=title, abstract, heading word, drug trade name, original title, device manufacturer,  
12 drug manufacturer, device trade name, keyword]  
13 (efficacy\* or effectiv\*).mp. [mp=title, abstract, heading word, drug trade name, original  
14 title, device manufacturer, drug manufacturer, device trade name, keyword]  
15 exp prognosis/  
16 (prognos\* or treatment\* or surgery\*).mp. [mp=title, abstract, heading word, drug trade  
17 name, original title, device manufacturer, drug manufacturer, device trade name,  
18 keyword]

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3 12 (review or letter or comment or editorial).pt.  
4 13 (radiotherapy\* or stage\* or grade\*).mp. [mp=title, abstract, heading word, drug trade  
5 name, original title, device manufacturer, drug manufacturer, device trade name,  
6 keyword]  
7 14 (anxiety\* or worry\* or fatalism\* or hopelessness\* or denial\* or avoid\*).mp. [mp=title,  
8 abstract, heading word, drug trade name, original title, device manufacturer, drug  
9 manufacturer, device trade name, keyword]  
10 15 8 or 9 or 14  
11 16 10 or 11 or 12 or 13  
12 17 exp cancer screening/  
13 18 health behaviour.mp. or exp health behavior/  
14 19 ((behaviour or behavior) and health).mp. [mp=title, abstract, heading word, drug trade  
15 name, original title, device manufacturer, drug manufacturer, device trade name,  
16 keyword]  
17 20 (screen\* and (uptake or attendance or intention or adherence)).mp. [mp=title, abstract,  
18 heading word, drug trade name, original title, device manufacturer, drug manufacturer,  
19 device trade name, keyword]  
20  
21 21 20 and 1  
22 22 15 or 17 or 18 or 19 or 21  
23 23 22 and 7  
24 24 23 not 16  
25 25 limit 24 to yr="2000 -Current"  
26 26 25 not review.mp. [mp=title, abstract, heading word, drug trade name, original title,  
27 device manufacturer, drug manufacturer, device trade name, keyword]  
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### ***PsycInfo***

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30 S20 S19 NOT review Limiters - Publication Year: 2000-2015  
31 S19 S17 NOT (S10 OR S11 OR S12)  
32 S18 S17 NOT (S10 OR S11 OR S12)  
33 S17 S7 and (S8 or S9 or S13 or S15 or S16)  
34 S16 health AND (behaviour OR behavior)  
35 S15 S14 AND S1  
36 S14 screen\* AND (uptake OR attendance OR intention OR adherence)  
37 S13 MM "Cancer Screening"  
38 S12 (prognos\* OR treatment\* OR surgery\*) AND (S10 OR S11)  
39 S11 prognos\* OR treatment\* OR surgery\*  
40 S10 DE "Prognosis"  
41 S9 efficacy or effectiv\* or worry\* or anxiety\* or hopelessness\* or denial\*  
42 S8 percep\* OR perceive\* OR understand\* OR understood\* OR accura\* OR comprehen\*  
43 S7 (S1 AND S6)  
44 S6 (S4 OR S5)  
45 S5 DE "Risk Assessment"  
46 S4 (S2 AND S3)  
47 S3 score\* OR model\* OR predict\* OR tool\*  
48 S2 risk\*  
49 S1 DE "Neoplasms" OR DE "Benign Neoplasms" OR DE "Breast Neoplasms" OR DE  
50 "Endocrine Neoplasms" OR DE "Leukemias" OR DE "Nervous System Neoplasms"  
51 OR DE "Terminal Cancer"  
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2 **Supplementary file 2.** Quality assessment of included studies  
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5 Author, date	6 Study addressed a clearly focused issue	7 Use of an appropriate method / Randomisation (for RCTs)	8 Recruitment / comparability of study groups at baseline	9 Blinding (for RCTs)	10 Exposure measurement	11 Outcome measurement	12 Comparability of study groups during study (for RCTs)	13 Follow up (for longitudinal studies)	14 Confounding factors (for non-RCTs):	15 Overall
16 Bodurtha, 2009	●	●	●	●	●	●	●	●	n/a	M-H
17 Bowen 2006	●	●	●	●	●	●	●	●	n/a	H
18 Bowen 2010	●	●	●	●	●	●	●	●	n/a	H
19 Davis, 2004	●	●	●	●	●	●	●	●	n/a	M
20 Dillard, 2006a	●	●	●	●	●	●	●	●	n/a	L-M
21 Dillard, 2006b	●	●	●	●	●	●	●	●	n/a	L-M
22 Emmons, 2004	●	●	●	●	●	●	●	●	n/a	M-H
23 Giles, 2001	●	●	●	●	●	●	●	●	n/a	M
24 Glanz, 2013	●	●	●	●	●	●	●	●	n/a	M
25 Glazebrook 2006	●	●	●	●	●	●	●	●	n/a	M
26 Greene, 2003	●	●	●	●	●	●	●	●	n/a	L-M
27 Han, 2015	●	n/a	●	n/a	●	●	n/a	n/a	●	M
28 Helmes, 2006	●	●	●	●	●	●	●	●	n/a	M
29 Holloway, 2003	●	●	●	●	●	●	●	●	n/a	M-H
30 Kaplan, 2014	●	●	●	●	●	●	●	●	n/a	L-M
31 Lau, 2015	●	●	●	n/a	●	●	n/a	n/a	●	L-M

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Lipkus , 2006	●	●	•	•	●	●	•	●	n/a	M
Lipkus, 2001a	●	●	•	•	●	●	•	•	•	L
Lipkus, 2001b	●	●	•	•	n/a	●	●	●	●	M
Lipkus, 2005	●	•	•	•	n/a	●	•	●	●	L
Livaudais- Toman, 2015	●	●	●	●	n/a	●	●	●	n/a	H
McCaul, 2003	●	●	•	•	●	●	•	●	n/a	L
Quillin, 2004	●	●	•	•	●	●	•	●	n/a	M
Rimer 2002	●	●	•	•	●	●	●	●	n/a	M
Rubenstein, 2011	●	●	●	•	●	●	●	●	n/a	M
Schnoll, 2005	●	●	•	n/a	●	●	•	•	●	M-H
Schroy, 2011	●	●	●	•	●	●	●	●	n/a	M-H
Schroy, 2012	●	●	●	•	●	●	●	●	n/a	H
Sequist 2011	•	•	•	•	•	•	•	n/a	n/a	M
Timmermans 2012	•	•	•	•	•	•	•	n/a	n/a	M
Trevena 2008	•	•	●	●	•	•	•	•	n/a	M
Wang, 2012	●	●	●	•	●	•	●	●	n/a	M
Weinstein, 2004	●	•	•	•	●	•	•	•	n/a	L-M

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● Low (L) ● Medium (M) ● High (H)

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# PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
<b>TITLE</b>			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
<b>ABSTRACT</b>			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	2
<b>INTRODUCTION</b>			
Rationale	3	Describe the rationale for the review in the context of what is already known.	3
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	4
<b>METHODS</b>			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	4
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	5
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	4
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Supplementary file 1
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	5
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	5/6
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	5/6
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	6
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	6/7
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., $I^2$ for each meta-analysis).	6/7





# PRISMA 2009 Checklist

Page 1 of 2

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	6
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	N/A
<b>RESULTS</b>			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	7 and Figure 1
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	Table 1 and Table 2
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	Supplementary file 2
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	8-17 and Figures 2, 3 and 4
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	8-17 and Figures 2, 3 and 4
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	N/A
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	N/A
<b>DISCUSSION</b>			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	17/18
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	19/20
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	18-20
<b>FUNDING</b>			



# PRISMA 2009 Checklist

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Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	21
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From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit: [www.prisma-statement.org](http://www.prisma-statement.org).

Page 2 of 2

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# BMJ Open

## Change in intention and behaviour following interventions incorporating information about cancer risk amongst the general population: a systematic review and meta-analysis of randomised controlled trials

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2017-017717.R1
Article Type:	Research
Date Submitted by the Author:	12-Oct-2017
Complete List of Authors:	Usher-Smith, Juliet; The Primary Care Unit, Institute of Public Health Silarova, Barbora; MRC Epidemiology Unit, Sharp, Stephen; University of Cambridge, MRC Epidemiology Unit Mills, Katie; The Primary Care Unit, Institute of Public Health Griffin, Simon; The Primary Care Unit, Institute of Public Health
<b>Primary Subject Heading</b>:	Communication
Secondary Subject Heading:	Oncology
Keywords:	ONCOLOGY, PREVENTIVE MEDICINE, PUBLIC HEALTH

SCHOLARONE™  
Manuscripts

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3 **Change in intention and behaviour following interventions incorporating information**  
4 **about cancer risk amongst the general population: a systematic review and meta-analysis**  
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6 **of randomised controlled trials**  
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10 Juliet A Usher-Smith<sup>1</sup>, Barbora Silarova<sup>2</sup>, Stephen J Sharp<sup>2</sup>, Katie Mills<sup>1</sup>, Simon J Griffin<sup>1</sup>  
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## ABSTRACT

**Objective** To provide a comprehensive review of the impact on intention and behaviour, including screening uptake, of interventions incorporating information about cancer risk targeted at the general adult population.

**Design** A systematic review and random effects meta-analysis

**Data sources** An electronic search of Medline, EMBASE, CINAHL and PsychINFO from 01/01/2000 to 01/07/2017.

**Inclusions criteria** Randomised controlled trials of interventions including provision of a personal estimate of future cancer risk based on two or more non-genetic variables to adults recruited from the general population including at least one behavioural outcome.

**Results** We included 19 studies reporting 12 outcomes. There was significant heterogeneity in interventions and outcomes between studies. There is evidence that interventions incorporating cancer risk information do not affect intention to attend or attendance at screening (Relative risk (RR) 1.00 (0.97-1.03)). There is limited evidence that they increase intention to tan, smoking abstinence, sun protection, adult skin self-examination and breast examination but do not increase intention to protect skin, smoking cessation or parental child skin examination. No studies reported changes in diet, alcohol consumption or physical activity.

**Conclusions** Interventions incorporating cancer risk information do not affect uptake of screening but there is limited evidence of effect on some health behaviours. Further research, ideally including objective measures of behaviour, is needed before cancer risk information is incorporated into routine practice for health promotion in the general population.

**Key words:** Cancer, risk, systematic review, intervention, prevention, communication

### Strengths and limitations of this study

- This systematic review is the first comprehensive review of interventions incorporating cancer risk on intention and behaviour of individuals in the general population.
- The use of a broad search strategy across multiple databases enabled us to identify 19 randomised controlled trials reporting the impact of interventions incorporating cancer risk information on 12 outcomes.
- However, there was large heterogeneity across the studies, including the content of interventions and the outcome measures. This meant it was only possible to meta-analyse one outcome, attendance at screening, and in many studies separating the effect of the risk information alone from additional elements of the interventions was not possible.

## INTRODUCTION

In 2006 the US National Cancer Institute recognised risk prediction models as an ‘area of extraordinary opportunity’<sup>1</sup>. Since then an increasing number of risk prediction models have been developed. Such models can facilitate a personalised approach to cancer prevention and treatment and a more equitable and cost-effective distribution of finite resources by targeting screening and prevention activities at those most likely to benefit. Furthermore, being able to estimate, communicate and monitor individual risk and demonstrate the impact of lifestyle change on future risk of cancer may complement wider collective approaches to shifting population distributions of behaviour, risk factors and cancer risk.

Research has shown that many individuals have incorrect perceptions of their risk of cancer<sup>2-4</sup> and that both over- and under-estimation are associated with maladaptive health behaviours<sup>5</sup>. Additionally, whilst up to 40% of all cancers are attributable to lifestyle factors<sup>6</sup>, only 3% of people are aware that being overweight can increase their risk of cancer and less than a third that physical activity could help reduce risk<sup>7-10</sup>. One in seven people additionally believe that lifetime risk of cancer is unmodifiable<sup>11</sup>. Most behaviour change theories suggest that perceived risk is important alongside other constructs such as self-efficacy, response efficacy in promoting behaviour change<sup>12,13</sup>. Providing individuals with estimates of their risk of cancer alongside other behaviour change interventions may therefore help motivate behaviour change at an individual level. It may also enable individuals to make more informed decisions about uptake of screening tests for cancer. This has led to the development of an increasing number of interventions incorporating information about cancer risk being developed.

Understanding the impact of interventions incorporating information about cancer risk on behaviour and intention to change behaviour before they are introduced into routine practice is

1  
2 important. Previous systematic reviews in this area have focused only on trials in primary  
3 care<sup>14</sup> or tailored information about cancer risk and screening<sup>15,16</sup>. In this review we aimed to  
4 provide a comprehensive synthesis of the impact of interventions incorporating information  
5 about cancer risk on intention and behaviour within the general adult population.  
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## 10 11 12 13 **METHODS**

14 We performed a systematic literature review following an a priori established study protocol  
15 (available on request). Reporting followed the PRISMA statement<sup>17</sup>.  
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19

### 20 21 22 **Search strategy**

23 We performed an electronic literature search of Medline, EMBASE, CINAHL and PsychINFO  
24 from January 2000 until July 2017 with no language limits using a combination of subject  
25 headings and free text incorporating ‘cancer’, ‘risk/risk factor/risk assessment’ and  
26 ‘prediction/model/score/tool’ (see Supplementary file 1 for the complete search strategies).  
27 We then extended the search by manually screening the reference lists of all included papers.  
28 We chose to begin the search in 2000 as the previous review of tailored information about  
29 cancer risk and screening had noted that computer delivered interventions, as would be  
30 required for calculating risk scores, were only described in publications from 2000 onwards<sup>15</sup>.  
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### 43 44 **Study selection**

45 We included studies if they were randomised controlled studies published as a primary  
46 research paper in a peer-reviewed journal, included adults with no previous history of cancer  
47 and included provision to individuals of a personal estimate of future cancer risk based on two  
48 or more non-genetic variables and reported at least one behavioural outcome. In order to focus  
49 on the provision of cancer risk to the general population, we excluded studies which had  
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1  
2 recruited participants on the basis of a personal or family history of cancer or following referral  
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4 to specialist cancer risk services. Vignette, before-and-after studies without a control group,  
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6 cross-sectional and qualitative studies were also excluded along with conference abstracts,  
7  
8 editorials, commentaries and letters.  
9

10  
11  
12  
13 Two reviewers (JUS and BS) each screened half of the titles and abstracts to exclude papers  
14  
15 that were clearly not relevant. A third reviewer (SG) independently assessed a random  
16  
17 selection of 5% of the papers screened by each of the first reviewers. The full text was  
18  
19 examined if a definite decision to exclude could not be made based on title and abstract alone.  
20  
21 Two reviewers (JUS and BS) independently assessed all full-text papers. We discussed papers  
22  
23 for which it was unclear whether or not the inclusion criteria were met at consensus meetings  
24  
25 with a third reviewer (SG). Papers written in languages other than English were translated into  
26  
27 English for assessment and subsequent data extraction.  
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### 32 **Data extraction**

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34 Two researchers (JUS+BS/KM) independently extracted data from studies included in the  
35  
36 review using a standardized data abstraction form to reduce bias. The data extracted included:  
37  
38 (1) Study characteristics (cancer type, study design, study setting, duration of follow-up); (2)  
39  
40 selection of participants (inclusion criteria, method of recruitment/randomisation); (3)  
41  
42 participant characteristics (age, level of cancer risk, sample size); (4) the intervention (risk tool  
43  
44 used, method and format of risk communication, additional information or follow-up  
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46 provided), and (4) measured outcome(s). Reviewers were not blinded to publication details.  
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### 52 **Quality assessment**

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54 We conducted quality assessment at the same time as data extraction using a checklist based on  
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1  
2 the Critical Appraisal Skills Programme (CASP) guidelines<sup>18</sup> as an initial framework. This  
3  
4 includes eight questions concerning whether the study addressed a clearly focused issue, the  
5  
6 method of recruitment and randomisation, whether blinding was used, the measurement of the  
7  
8 exposure and outcome, the comparability of the study groups and the follow-up. Each study  
9  
10 was then classified as high, medium or low quality. No studies were excluded based on quality  
11  
12 alone.  
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### 15 16 17 **Data synthesis and statistical analysis** 18

19 For analysis, we grouped the measured outcomes into those relating to: 1) preferences or  
20  
21 intention to attend cancer screening; 2) cancer screening uptake; 3) intention or motivation to  
22  
23 change health-related behaviour; and 4) change in health-related behaviour. It was only  
24  
25 possible to pool results for screening attendance. For this we used random effects meta-  
26  
27 analysis<sup>19</sup> and the ‘metan’ package in Stata. We present intervention effects as relative risk  
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29 rather than odds ratios to avoid overestimating the risk<sup>20</sup>. We estimated the heterogeneity  
30  
31 between studies using the  $I^2$  statistic. All analyses were conducted using statistical software  
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33 package Stata/SE version 12.  
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## 39 **RESULTS** 40

41 After duplicates were removed, the search identified 38,906 papers. Of these, 35,604 were  
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43 excluded at title and abstract level and a further 183 after full-text assessment. After title and  
44  
45 abstract screening by the first reviewers (JUS and BS), no additional papers met the inclusion  
46  
47 criteria in the random 5% screened by the second reviewer (SG). The most common reasons  
48  
49 for exclusion at full-text level were that the papers did not include provision of a personal risk  
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51 estimate ( $n=62$ ), did not include any data on predefined outcomes ( $n= 37$ ), were conference  
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2 abstracts ( $n=20$ ), or were not primary research ( $n=16$ ) (Figure 1). Five further papers were  
3  
4 identified through citation searching, giving 19 studies included in the analysis.  
5  
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7  
8 A summary of the participants and setting of those 19 studies is shown in Table 1. With the  
9  
10 exception of three studies conducted in the UK<sup>21-23</sup>, all studies took place in the USA. Most  
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12 recruited participants from those attending primary care clinics ( $n=3$ ), or from lists of  
13  
14 potentially eligible individuals from electronic medical records ( $n=7$ ), telephone services  
15  
16 ( $n=1$ ), insurance records ( $n=1$ ) or survey companies ( $n=1$ ). Two recruited through schools,  
17  
18 community centres and universities, one from those calling a cancer information service and  
19  
20 three used public advertisements.  
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24  
25 In eight studies information was provided about risk of breast cancer, in five about risk of  
26  
27 colorectal cancer, in three risk of skin cancer, one lung cancer, one cervical cancer and one  
28  
29 multiple cancers. Further details of the risk models used to calculate the risk estimate provided  
30  
31 to participants and the format of the intervention(s) are given in Table 2. All eight studies  
32  
33 providing information about breast cancer risk used the Gail risk model<sup>24</sup>. This was the first  
34  
35 risk model developed for breast cancer and includes age, age at menarche, age at first live  
36  
37 birth, number of previous biopsies, number of biopsies showing atypical hyperplasia, and  
38  
39 number of first-degree relatives with breast cancer. Where details were given ( $n=3$ ), all studies  
40  
41 on colorectal cancer used the Harvard Cancer Risk tool<sup>25</sup> which includes family history, height  
42  
43 and weight, alcohol consumption, vegetable and red meat consumption, physical activity,  
44  
45 screening history, a history of inflammatory bowel disease, and use of aspirin, folate and  
46  
47 female hormones. Other risk models used were the Liverpool Lung Project model<sup>26</sup>, Family  
48  
49 Healthware tool<sup>27</sup>, Wilkinson score for cervical cancer<sup>28</sup> and the brief skin cancer risk  
50  
51 assessment tool (BRAT)<sup>29</sup> adapted for children. Quality assessment for each of studies is  
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1  
2 provided in Supplementary file 2. Seven were assessed as high or medium/high quality, 11 as  
3  
4 medium quality and one as medium/low.  
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9 Overall findings and evidence synthesis along with the number and quality of studies  
10  
11 addressing each outcome are summarised in Table 3.  
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## 15 **Preferences and intentions for screening**

### 16 *Preferences for screening*

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18  
19 Two RCTs reported participants' views about screening. In the cluster-randomised trial by  
20  
21 Holloway *et al.*<sup>21</sup> participants who received a 10 minute counselling session including  
22  
23 information about relative and absolute risks of cervical cancer integrated within a smear test  
24  
25 appointment were significantly less likely to state a preference for the next interval for cervical  
26  
27 screening to be 12 months or less than those who received usual care (OR: 0.51 (95%CI: 0.41-  
28  
29 0.64)). The second study by Lipkus *et al.*<sup>30</sup> reported attitudinal ambivalence towards faecal  
30  
31 occult blood test (FOBT) screening measured by their agreement with three Likert-style items  
32  
33 stating that they had "mixed feelings", felt "torn" and had "conflicting thoughts" about whether  
34  
35 to get screened for CRC using an FOBT. Participants who received estimates of either  
36  
37 absolute or absolute plus comparative risk alongside written information about CRC screening  
38  
39 had significantly lower ambivalence than those who received the same written information  
40  
41 without tailored CRC risk information (p<0.05).  
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### 48 *Intention to attend cancer screening*

49  
50 Eight studies assessed intentions to attend cancer screening: five for mammography and four  
51  
52 for CRC screening. Five showed no effect of risk information, three in which the only  
53  
54 substantial difference between the intervention and control groups was the provision of a risk  
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1  
2 estimate<sup>31–33</sup>. Bodurtha *et al.*<sup>31</sup> found no significant differences at 18 months between those  
3  
4 randomised to receive either printed sheets with their 5-year and lifetime estimates of breast  
5  
6 cancer risk alongside information addressing barriers to mammography, breast cancer  
7  
8 seriousness and benefits of yearly mammography, or general information about breast cancer  
9  
10 prevention practices not tailored to their risk level (OR after adjusting for baseline intentions  
11  
12 and recruitment site: 0.97 (95%CI: 0.70 to 1.33)). Davis *et al.*<sup>34</sup> reported that women who  
13  
14 received a brief intervention over the telephone including information about lifetime risk of  
15  
16 cancer and screening recommendations were no more likely at one month to report being in the  
17  
18 maintenance stage (having had one mammogram in the past two years and two or more in the  
19  
20 past four years and planning to get another on schedule) than the control group who received  
21  
22 no intervention (67% in the intervention group compared to 68% in the control group). Helmes  
23  
24 *et al.*<sup>35</sup> reported changes in a single breast health intentions measure which included intention  
25  
26 to have mammography, clinical breast examination, and breast self-examination. They found  
27  
28 no significant differences at baseline (p=0.23) or three month follow-up (p=0.46) between  
29  
30 women who received estimates of their lifetime risk of breast cancer along with information  
31  
32 about breast awareness either face-to-face or over the telephone and a control group who  
33  
34 received no intervention. Schroy *et al.*<sup>32</sup> randomised participants to complete an interactive 20-  
35  
36 30 minutes computer-based decision aid which either did or did not include a personalised risk  
37  
38 assessment. There was no difference between groups on a five-point scale of how sure they  
39  
40 were that they would schedule a CRC screening test (mean scores 4.3 (SD: 1.0) for both  
41  
42 groups). Trevena *et al.*<sup>33</sup> similarly reported no effect on intention to have CRC screening of a  
43  
44 20-page decision aid including information about baseline risk and absolute reduction in CRC  
45  
46 mortality with screening, compared to a 3-page booklet with information and recommendations  
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48 about screening.  
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2 The two studies reporting an effect were by Lipkus *et al.*<sup>30</sup> and Seitz *et al.*<sup>36</sup>. In Lipkus *et al.*  
3  
4 intention to complete an FOBT that would be given to them within the following month was  
5  
6 measured on a seven-point Likert scale. The intentions reported by participants who received  
7  
8 absolute risk (mean 3.65,  $n=40$ ) or absolute plus either low (mean 6.43,  $n=38$ ) or high (mean  
9  
10 6.65,  $n=39$ ) comparative risk information were statistically significantly higher ( $p<0.05$ ) than  
11  
12 those participants in the control group who were provided with the same written information  
13  
14 but without risk estimates (mean 2.21,  $n=43$ ). The mean intention reported by the group which  
15  
16 received the comparative risk was also significantly higher than for the absolute risk only  
17  
18 group. In Seitz *et al.* women were separated into those with an estimated 10-year breast cancer  
19  
20 risk above or below 1.5%. Intention to wait until age 50 before undergoing a mammogram was  
21  
22 measured for those with a risk  $<1.5\%$  and intention to start or continue to undergo  
23  
24 mammograms in their 40s for those with a risk  $\geq 1.5$ . In the low risk group, all risk-based  
25  
26 intervention conditions resulted in a significant increase in the percentage of women planning  
27  
28 to wait to age 50. However, in the high risk group no such significant difference was seen.  
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34 The eighth study by Lipkus *et al.*<sup>37</sup> reported the difference in intentions to get a mammogram  
35  
36 between one group that received a one-page handout including their estimated absolute risk  
37  
38 and another group that received the same handout plus information concerning how their risk  
39  
40 compared to a woman of their age and race at the lowest level of risk. Immediately after the  
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42 provision of risk information, overall 2.5%, 67.8%, and 24.8% reported that the risk  
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44 information lowered, did not affect, or increased their intentions to undergo a mammogram  
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46 respectively, with no differences between the groups.  
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### 52 **Attendance at screening**

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2 Twelve RCTs reported attendance at screening: six for mammography<sup>31,34,38-41</sup>; five for  
3 colorectal cancer<sup>30,32,33,38,42</sup>, and one for cervical cancer<sup>21</sup>. Except for one high quality RCT in  
4 which the intervention group received information sheets including general information on  
5 breast cancer risk alongside personalised risk information and telephone counselling and the  
6 offer for more intensive group or genetic counselling<sup>41</sup>, all showed no effect of the risk-based  
7 interventions as shown in the meta-analysis (Figure 2) with a combined RR of 1.02 (95%CI:  
8 0.98-1.03, I<sup>2</sup>: 61.6%).  
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### 19 **Intention to change health-related behaviours**

#### 20 *Intention to tan or protect skin*

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22 One RCT by Greene and Brinn measured intention to tan on a six-item Likert-type scale and  
23 intention to protect skin using a three-item scale<sup>43</sup>. Participants who completed a self-  
24 assessment risk score alongside receiving generic information about tanning, tanning beds and  
25 sun exposure reported significantly decreased intentions to use tanning beds than those  
26 receiving the same generic information alone (2.68, *n*=70 compared to 3.19, *n*=71, *p*<0.05). In  
27 contrast there were no significant differences in intentions to protect skin (2.38, *n*=70  
28 compared to 2.49, *n*=71, *p*>0.05).  
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### 41 **Change in health-related behaviours**

#### 42 *Smoking status*

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44 One high quality RCT<sup>23</sup> reported the impact of risk information on smoking status. Receiving a  
45 personalised risk estimate in addition to a generic leaflet did not predict self-report smoking  
46 status at six months in current smokers (*p*=0.66) but was associated with an increased odds of  
47 remaining a former smoker in those who had recently quit (OR 1.91 (95%CI 1.03-3.55)).  
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### *Sun exposure and sun protection habits*

Two RCTs<sup>22,44</sup> measured sun protection habits by survey completion at baseline and follow up. One by Glanz *et al.* compared the effect on childhood sun exposure and sun protection habits of three mailings with personalised risk feedback, interactive skin cancer education materials and a family fun guide to a single mailing of standardised skin cancer information<sup>44</sup>. The other by Glazebrooke *et al.* compared usual care with a self-directed computer program including individualised feedback of risk alongside sections on skin protection, how to detect melanoma, dangers of sun exposure, how to check skin and how to reduce risk<sup>22</sup>. Both showed increases in overall sun protection habits (increase in sun protection habits index 0.19 in the intervention group compared to 0.14,  $p=0.02$ <sup>44</sup> and mean difference in skin protective behaviour score between intervention and control at six month follow-up 0.33 (95% CI 0.09, 0.57)<sup>22</sup>) with variable results for individual aspects including wearing a sun hat, wearing a shirt, wearing sunglasses, use of sun cream, number of sunburns, staying in the shade, and sun exposure during weekdays and weekends.

### *Tanning bed usage*

The RCT by Greene and Brinn<sup>43</sup> measured change in tanning behaviour and tanning bed usage. Participants who completed the self-assessment risk score reported lower rates of tanning bed usage in the previous month at follow-up (2.18,  $n=70$  compared to 3.76,  $n=71$ ,  $p<0.05$ ) but no difference in change in tanning behaviour from pre- to post-intervention (-1.25,  $n=70$  compared to -2.08,  $n=71$ ,  $p>0.05$ ).

### *Self/parent skin examination*

The two RCTs by Glanz *et al.* and Glazebrooke *et al.*, measured rates of skin examination in adults<sup>22</sup> or parents and children<sup>44</sup>. Both showed statistically significant increases among adults



1  
2 and parents receiving personalised risk information ( $p<0.05$ ) while the increase in parents  
3  
4 examining their children was not statistically significant ( $p=0.06$ ).  
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### 8 9 *Clinical breast examination and breast self-examination*

10 Three RCTs<sup>31,40,41</sup> measured rates of clinical breast examination and/or breast self-examination  
11 following provision of risk information. In the RCT by Bodurtha *et al.*, no significant  
12 differences were seen between those randomised to receive printed sheets including estimates  
13 of 5-year and lifetime risk of breast cancer alongside information addressing barriers to  
14 mammography, breast cancer seriousness and benefits of yearly mammography and those  
15 receiving general information about breast cancer prevention practices not tailored to their risk  
16 level for either frequency of clinical breast examination (crude rates: 91.4% vs 91.0%; adjusted  
17 OR: 1.00 (95%CI: 0.60 to 1.66)) or breast self-examination (crude rates: 56.8% vs 57.6%;  
18 adjusted OR: 0.95 (95%CI: 0.67 to 1.33)<sup>31</sup>. The other two studies, both by Bowen *et al.*, found  
19 significantly ( $p<0.01$ ) greater increases in the proportion reporting performing breast self-  
20 examination in the intervention groups (35% to 52% and 36% to 62%) compared with controls  
21 (33% to 36% and 38% to 40%)<sup>40,41</sup>. However, both these studies compared intensive  
22 interventions (four weekly 2-hour sessions led by a health counsellor<sup>40</sup> or information sheets  
23 plus telephone counselling and the offer of more intensive group or genetic counselling<sup>41</sup>) with  
24 delayed intervention.  
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## 45 **DISCUSSION**

46 This systematic review is, to our knowledge, the first review of the impact of interventions in  
47 all settings incorporating information about cancer risk on intention and behaviour in the  
48 general population. The findings show that such interventions do not affect intention to attend  
49 or attendance at screening. There is limited evidence that they increase intention to tan,  
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1  
2 smoking abstinence, sun protection, adult skin self-examination and breast examination but this  
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4 was not seen for intention to protect skin, smoking cessation or parental child skin  
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6 examination. There is a notable absence of studies assessing the impact on diet, physical  
7  
8 activity and alcohol consumption with only one reporting smoking status and none including  
9  
10 objective measures of behaviour.  
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15 Our finding that interventions incorporating information about cancer risk had no effect on  
16  
17 intention to attend or attendance at screening is consistent with a previous Cochrane review in  
18  
19 which personalised risk communication had little effect on the uptake of screening tests (fixed-  
20  
21 effect OR 0.95 (95% CI 0.78 to 1.15))<sup>16</sup>. However, as in that review, there was evidence of  
22  
23 increased concordance between screening preferences and recommendations and decreased  
24  
25 ambivalence. This supports the suggestion made in that review that personalised risk  
26  
27 information might be useful for shared and informed decision making. For example, in surveys  
28  
29 of participants about their knowledge and values for cancer screening decisions and decision-  
30  
31 making processes, only 21% report feeling extremely well informed<sup>45</sup> and the majority  
32  
33 overestimate lifetime risk of cancer incidence and mortality<sup>45,46</sup>. While providing individuals  
34  
35 with information about their cancer risk may therefore not influence overall rates of screening  
36  
37 it may contribute to the decision to take up screening or not at an individual level and support  
38  
39 shared decision making.  
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45 The absence of significant effects on health-related behaviours is also consistent with research  
46  
47 in other disease areas, such as cardiovascular disease, where systematic reviews have found  
48  
49 only few studies reporting behaviour change and no significant effects on lifestyle<sup>47-49</sup>. This is  
50  
51 perhaps not surprising given that behaviour change is influenced by many other factors,  
52  
53 including health beliefs, social context, the environment, and personal attributes such as time  
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1  
2 orientation<sup>12,13</sup>. However, there was no evidence that interventions that include information  
3  
4 about cancer risk result in harm through false reassurance and the adoption of unhealthy  
5  
6 behaviours. This is important as on average many of the general population overestimate their  
7  
8 own risk of cancer<sup>30,35,40,50-52</sup> and so if information about cancer risk were routinely provided  
9  
10 within clinical practice large numbers would be receiving an estimate lower than their prior  
11  
12 perceptions.  
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17 The main strengths of this review are the systematic search of multiple electronic databases and  
18  
19 the broad inclusion criteria. This allowed us to include studies that assess the impact of  
20  
21 interventions incorporating cancer risk information on multiple behavioural outcomes.  
22

23  
24 However, from nearly 40,000 titles and abstracts, we only included 14 with an additional 5  
25  
26 found through citation searching. This highlights the challenge in identifying studies in this  
27  
28 area in which the primary purpose may not be related to the provision of risk information.  
29

30  
31 There was also significant heterogeneity in the outcome measures included, duration of follow-  
32  
33 up and method of recruitment across the included studies. For all outcomes except attendance  
34  
35 at screening there were either too few studies to meaningfully pool results or each study used  
36  
37 different non-comparable measures. The duration of follow-up varied from 1 to 18 months.  
38

39  
40 Although this makes pooling the findings more difficult, the studies with shorter follow-up  
41  
42 were those with intention as the outcome measures and, of the 10 studies reporting health-  
43  
44 related behaviours, five had a follow-up period of a year or more and three a period of six  
45  
46 months. It is therefore unlikely that the studies as a whole were too short to detect changes in  
47  
48 behaviour or reflected only immediate un-sustained changes.  
49

50  
51  
52 A further limitation is that many of the interventions consisted of provision of risk information  
53  
54 alongside a range of additional information, either written or delivered in person or in groups.  
55

1  
2 Separating the effect of the risk information from those additional elements of the interventions  
3  
4 was therefore not possible. However, we chose not to exclude these studies from this review  
5  
6 because it is unlikely that risk information would be incorporated into routine practice in  
7  
8 isolation and, if anything, including them would overestimate the effect of the risk information.  
9  
10 It is also possible that the findings do not reflect the potential impact of interventions  
11  
12 incorporating information about cancer risk on the general population as a whole: half of the  
13  
14 included studies focused on female cancers and so only recruited women and all were subject  
15  
16 to recruitment bias with the participants who agreed to take part potentially more interested in  
17  
18 their cancer risk or more healthy, resulting in a bias in either direction.  
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24 In addition to these specific limitations of our review, the findings also suggest a number of  
25  
26 areas for future research. In particular, the absence of studies assessing the impact on diet,  
27  
28 physical activity and alcohol consumption, and only one study reporting smoking cessation,  
29  
30 demonstrate the need for trials assessing change in these behaviours, preferably measured  
31  
32 objectively, including measures of other theory based determinants of behaviour change (for  
33  
34 example, self-efficacy). Only with such data will we be able to assess whether such  
35  
36 individualised approaches have a place alongside population-wide prevention strategies.  
37  
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47  
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## 50 **Contributors**

51  
52 JUS developed the protocol, completed the search, screened articles for inclusion, extracted  
53  
54 data, synthesized the findings, interpreted the results and drafted the manuscript. BS developed  
55  
56

1  
2 the protocol, screened articles for inclusion, extracted data, interpreted the results and critically  
3 revised the manuscript. SS synthesized the findings and critically revised the manuscript. KM  
4 extracted data, interpreted the results and critically revised the manuscript. SJG developed the  
5 protocol, screened articles for inclusion, interpreted the results and critically revised the  
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36 collection, analysis and interpretation of data; in the writing of the report; or decision to submit  
37 the article for publication.  
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### 43 **Data sharing**

44 All data are available from the reports or authors of the primary research. No additional data is  
45 available.  
46  
47  
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### 52 **Competing Interests**

53 All authors have completed the Unified Competing Interest form at  
54 [www.icmje.org/coi\\_disclosure.pdf](http://www.icmje.org/coi_disclosure.pdf) (available on request from the corresponding author) and  
55  
56

1  
2 declare that (1) they have no support from or relationships with companies that might have an  
3 interest in the submitted work in the previous 3 years; (2) their spouses, partners, or children  
4 have no financial relationships that may be relevant to the submitted work; and (3) they have  
5 no non-financial interests that may be relevant to the submitted work.  
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18

19 All authors had full access to all of the data in the study and can take responsibility for the  
20 integrity of the data and the accuracy of the data analysis  
21  
22  
23

24 The corresponding author affirms that the manuscript is an honest, accurate, and transparent  
25 account of the study being reported; that no important aspects of the study have been omitted;  
26 and that any discrepancies from the study as planned (and, if relevant, registered) have been  
27 explained.  
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## 32 33 **FIGURE LEGENDS**

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38 Figure 1. PRISMA flow diagram

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40 Figure 2. Relative risk for adherence to recommended screening post intervention. CRC –  
41 colorectal cancer; FOBT – faecal occult blood test; AR – absolute risk; CR – comparative risk  
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**Table 1.** Details of the setting and key outcomes of the included studies

Author, year	Cancer site(s)	Follow-up	Setting and participants	Risk level / co-morbidities	Outcome(s)	Quality*
Bodurtha 2009	Breast	18 months	899 women with no history of breast cancer recruited from waiting rooms of four women's health clinics	Not given	Mammography, clinical breast examinations, breast self-examination, mammography intentions	M-H
Bowen 2006	Breast	6 and 24 months	150 sexual minority women recruited via public advertisements	Mean Gail lifetime risk 12%	Breast self-examination, breast cancer screening	H
Bowen 2010	Breast	12 months	1,366 women recruited via purchased lists of telephone numbers with no previous diagnosis of breast cancer	Mean Gail lifetime risk 12%	Breast self-examination, mammography	
Davis, 2004	Breast	1 month	392 women with no history cancer calling the Cancer Information Service	27% 2-6% lifetime risk; 32% 6-9% lifetime risk; 41% 9-46% lifetime risk	Adherence to breast cancer screening, intention for breast cancer screening	M
Glanz 2013	Skin	16 weeks	Convenience sample of 1047 parents not currently being treated for skin cancer recruited through schools and community centres	38% high risk	Sun protection habits, sun exposure, skin examination by parents	M
Glazebrook 2006	Skin	6 months	589 recruited from 10 primary care practices from a convenience sample of appointments	Not given	Sun protection habits	M
Greene 2003	Skin	3-4 weeks	141 undergraduates at one university who received extra credit for participation	Not given	Intention to tan, actual tan bed usage	L-M
Helmes, 2006	Breast	3 months	Random sample of 340 members of state healthcare system with no history of breast/ovarian cancer or testing for cancer risk	Mean 9.5% (3.2) lifetime risk	Intention to have mammogram and clinical breast examination, intention to do breast self-examination	M
Holloway, 2003	Cervical	0, 4 years	1890 women attending routine cervical smear test at one of 29 GP practices	78-80% very low risk; 20-22% low risk	Preference for future screening interval, actual screening behaviour	M-H
Lipkus 2006	Colorectal	0	160 members of general public with no history of CRC or screening for CRC recruited through newspaper advertisements	Not given	Ambivalence, intention to screen using a FOBT, actual FOBT screening rates	M
Lipkus, 2001	Breast	0	121 members of general public recruited through newspaper advertisements	Mean 10 year risk 2.65% (SD 1.13)	Mammography screening and intentions	M
Rimer 2002	Breast	1 and 2 years	752 women aged 40-44 and 50-54 enrolled in a personal care plan	Mean 10 year risk 2.7%	Mammography	M
Rubenstein 2011	Breast, ovarian, colon	6 months	3786 patients from primary care clinic records with no history of colon, breast or ovarian cancer invited by mail following record review	34% moderate or strong risk of $\geq 1$ of the cancers	CRC screening, mammography	M

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3	Schroy, 2011	Colorectal	0	666 patients due for bowel screening identified from monthly audits of one hospital's electronic medical record	Average	Preferences, satisfaction with the decision-making process, screening intentions, and test concordance	M-H
4							
5	Schroy, 2012	Colorectal	0, 1, 3, 6 and 12 months	825 patients due for bowel screening identified from monthly audits of one hospital's electronic medical record	Average	Completion of a CRC screening test	H
6							
7	Seitz 2016	Breast	0	2,918 women aged 35-49 with no history of breast cancer or a genetic mutation in BRCA1 or BRCA2 recruited through a survey company	42% 10 year risk <1.5% (mean 1.08 SD 0.01); 58% 10 year risk ≥1.5% (mean 2.53 SD 0.04)	Mammography intentions	M
8							
9	Sequist 2012	Colorectal	1 and 4 months	1,103 patients from 14 ambulatory health centres who were overdue for colorectal cancer screening	Average	CRC screening	M
10							
11	Sherratt 2016	Lung	6 months	297 current and 216 recent former smokers aged 18-60 without a history of lung cancer and attending smoking cessation services	Not given	Smoking status	H
12							
13	Trevena 2008	Colorectal	1 month	314 patients recruited from 6 primary care practices without a history of colorectal cancer	Not given	Screening intentions, CRC screening	M
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RCT – randomised controlled trial; CRC – colorectal cancer; CT computerised tomography; FOBT – faecal occult blood test

\* L – low, M – medium, H - high

**Table 2.** Details of the risk-based interventions in each of the included studies

Author, year	Risk tool	Intervention group(s)	Comparison (where applicable)	Format of risk
Bodurtha 2009	Gail model (5 year and lifetime)	Information sheets with risk level and handouts addressing traditional constructs of Health Belief Model including barriers to mammography, breast cancer seriousness, individual risk for breast cancer, and benefits of yearly mammography	General information about breast cancer prevention practices, including mammography	Usual (<15%), Moderate (15-30%) or Strong (>30%)
Bowen 2006	Gail model (5 year, 10 year and at age 79)	Four weekly 2-hour sessions led by a health counsellor focusing on risk assessment and education, screening, stress management and social support	Delayed intervention	No details given
Bowen 2010	Gail model (lifetime)	Information sheets with general information on breast cancer risk and personalised risk information plus telephone counselling and offer for more intensive group or genetic counselling	Delayed intervention	Bar graph of absolute lifetime risk along with age-appropriate estimates for the "average risk" woman
Davis, 2004	BRCA tool (updated version of Gail model) (lifetime)	10min brief intervention designed to increase accuracy of perceived risk including results of risk assessment and screening recommendations tailored to participant's stage of adoption of mammography and follow up written information	No intervention	Verbal over the telephone. No additional details given.
Glanz 2013	Children's BRAT	Three mailings with personalised risk feedback, interactive skin cancer education materials, a family fun guide and suggestions for overcoming barriers and reminders to engage in preventive practices	Single mailing of standardised skin cancer information	No details given
Glazebrooke 2006	No details given	Self-directed computer program including sections on skin protection, how to detect melanoma, dangers of sun exposure, how to check skin, how to reduce risk and individualized feedback of risk	Usual care	Comparative risk
Greene 2003	Relative risk adapted from "ADD Wants to Convert"	Self-assessment of risk alongside generic messages about tanning, tanning beds and sun exposure	Generic messages about tanning, tanning beds and sun exposure	Numerical scale from 1-36
Helmes, 2006	Gail model (lifetime)	Face-to-face or telephone intervention consisting of 8 items: 1) a personal risk sheet ; 2) a personal computer-drawn pedigree; 3) a 23 page participant booklet; 4) Breast self-examination brochure; 5) Pap smear and mammography	No intervention	Bar charts of absolute % risk with numerical % alongside for the individual, an average-risk woman, and a high-risk woman

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3			brochure; 6) BSE shower card; 7) pictures of chromosomes		
4			and gene mutations; 8) a list of community resources for		
5			breast cancer		
6	Holloway,	Wilkinson score	Brief 10 minute counselling session integrated with smear	Usual care	Comparative and absolute risk in pictures
7	2003		test appointment including relative and absolute risks and		and numbers
8			then negotiation of appropriate screening intervals		
9	Lipkus 2006	Not given	Written information about CRC, CRC screening methods	Written information about	Narrative comparative risk
10			and CRC risk factors plus either 1) tailored CRC risk factor	CRC, CRC screening	
11			information or 2) tailored CRC risk factor information plus	methods, and CRC risk	
12			information on whether their total number of CRC risk	factors	
13			factors was greater or not than average		
14	Lipkus, 2001	Gail model (10	1 page handout describing the Gail model plus absolute risk	As for intervention group	Absolute risk +/- risk of a woman at the
15		year)	alone	plus how their risk compared	lowest level of risk as percentages in a pie
16				to a woman of their age and	chart
17				race at the lowest level of	
18				risk	
19	Rimer 2002	Gail model (10 year	Tailored print booklet and brief tailored newspaper plus	Usual care (postcard	Absolute risk as a percentage
20		and lifetime)	personalized risk	reminder)	
21	Rubenstein	Family Healthcare	Written personalized risk assessment and tailored prevention	Written generalized	Qualitative risk - weak, moderate or strong
22	2011	tool	messages	prevention messages	familial risk
23	Schroy, 2011	Harvard cancer risk	Interactive 20-30 min computer-based decision aid plus	Interactive 20-30 min	Thermograph, indicating where the
24		model (10 year)	personalized risk assessment	computer-based decision aid	participant is along with a description e.g.
25				alone	your risk is below average
26	Schroy, 2012	Harvard cancer risk	Interactive 20-30 min computer-based decision aid plus	As for intervention but	Qualitative framing (“very much below
27		model (10 year)	personalized risk assessment followed immediately by a	without personalized risk	average risk” to “very much above average
28			meeting with their providers to discuss screening and	assessment	risk”) with accompanying suggestions for
29			identify a preferred screening strategy. Providers received		behaviour modifications that might reduce
30			written notification hand-delivered by all the patients		risk, including a strong recommendation for
31			acknowledging that they were participating in the “CRC		screening, regardless
32			decision aid study” at the time of the visit to ensure that		of risk
33			screening was discussed		
34	Seitz 2016	Gail model (10	Online risk plus basic information about mammography and	No information or the same	Absolute risk and risk of an average-risk
35		year)	national recommendations plus either 1) statements about	basic information as	age-matched women as numeric frequencies
36			women making choices 2) untailored exemplars of women	intervention group	and icon arrays
37			making choices or 3) exemplars of similar women making		
38			choices		

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Sequist 2011	Harvard cancer risk model (10 year)	Personalized electronic message highlighting their overdue screening status and providing a link to a web-based tool to assess their risk	No contact	Comparative risk on 7-point ordinal scale from very-much below average to very-much above average and in interactive graphical format
Sherratt 2016	Liverpool Lung Project model (5 year at age 70)	Personalised risk plus booklet stating the association between smoking and lung cancer and highlighting that quitting smoking was the best thing to do	As for intervention but without personalized risk assessment	Verbal and written absolute risk if continue to smoke and if stop smoking alongside icon arrays
Trevena 2008	No details given	20 page booklet including personalized risk, absolute reduction in colorectal cancer mortality with screening over the next 10 years, probability of test outcomes from screening and information about how to get screened.	3 page booklet with information and recommendations about screening	Words and 1000-face diagrams

CRC – colorectal cancer

For peer review only



**Table 3. Summary of evidence on outcomes**

Outcome measure	Number of studies	Studies with significant positive effect	Studies with no effect	Best evidence synthesis
<b>Screening</b>				
Preferences for screening	2	1 medium/high quality and 1 high quality RCT	None	Evidence of positive effect
Intention to attend screening	8	1 medium quality RCT*	1 high quality, 1 medium/high quality and 4 medium quality RCTs*	Evidence of no effect
Attendance at screening	12	1 high quality RCT	2 high quality, 2 medium/high quality and 7 medium quality studies	Evidence of no effect
<b>Health-related behaviours</b>				
<b>Intention to change health-related behaviours</b>				
To tan	1	1 low/medium RCT	None	Limited evidence of positive effect
To protect skin	1	None	1 low/medium RCT	Limited evidence of no effect
<b>Health-related behaviours</b>				
Smoking cessation	1	None	1 high quality RCT	Limited evidence of no effect
Smoking abstinence	1	1 high quality RCT	None	Limited evidence of positive effect
Sun protection	2	2 medium quality RCTs		Indicative evidence of positive effect
Tanning bed usage	1	None	1 low/medium RCT	Limited evidence
Adult skin examination	2	2 medium quality RCTs	None	Indicative evidence of positive effect
Child skin examination	1	None	1 medium quality RCT	Limited evidence of no effect
Breast examination	3	2 high quality RCTs	1 medium/high RCT	Indicative evidence of positive effect
Diet	0	None	None	No evidence
Physical activity	0	None	None	No evidence
Alcohol	0	None	None	No evidence

\* 1 medium quality study reported a significant positive effect in low risk women and no effect in high risk women

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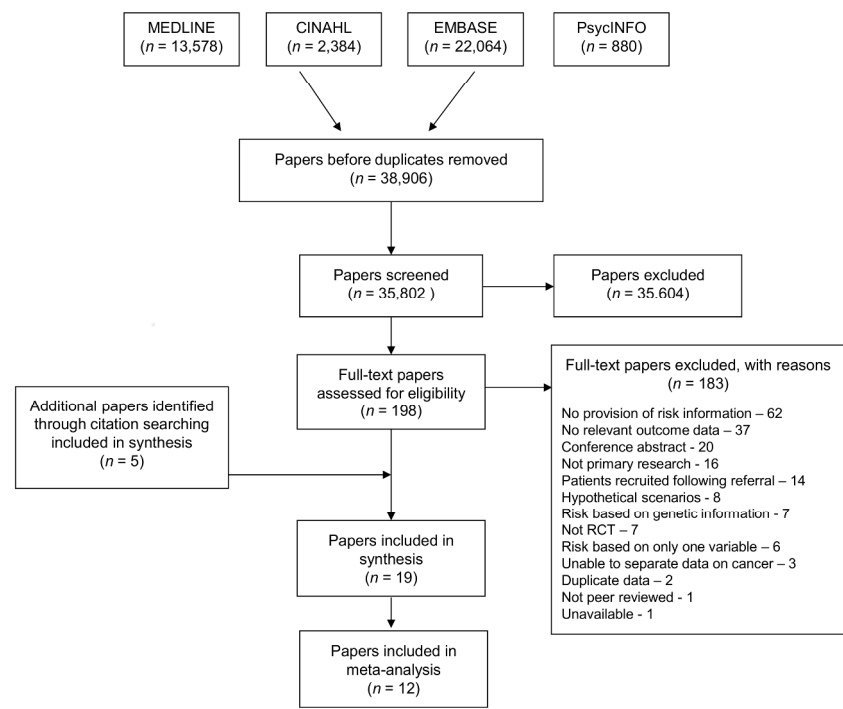


Figure 1. PRISMA flow diagram

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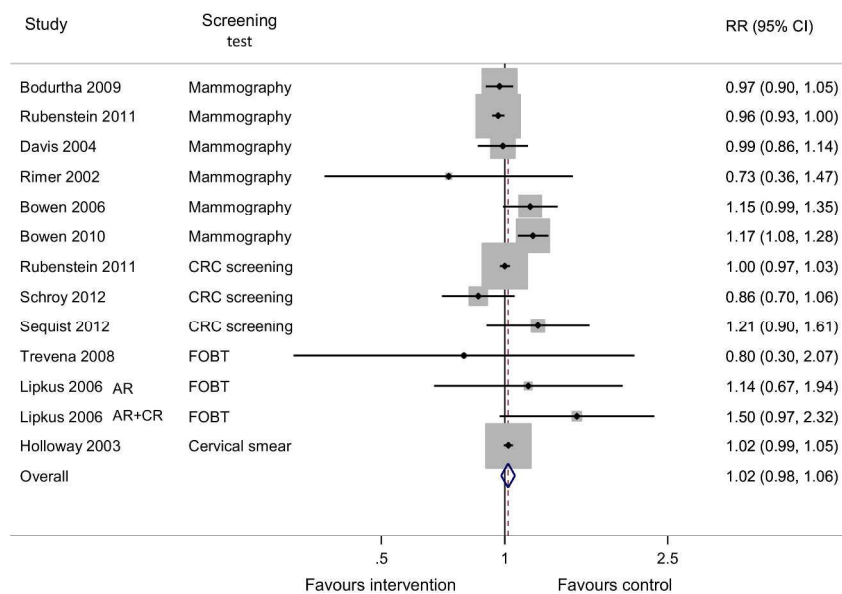


Figure 2. Relative risk for adherence to recommended screening post intervention. CRC – colorectal cancer; FOBT – faecal occult blood test; AR – absolute risk; CR – comparative risk

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3 **Supplementary file 1 – Complete search strategy**  
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9 S25 S13 NOT S15  
10 S24 S14 OR S16 OR S17 OR S21 OR S22 OR S23  
11 S23 ( behaviour OR behavior ) AND health  
12 S22 (MH "Health Behavior+") OR (MH "Risk Reduction Behavior+")  
13 S21 S18 OR S20  
14 S20 S19 AND S1  
15 S19 screen\* AND uptake OR attendance OR intention OR adherence  
16 S18 (MM "Early Detection of Cancer/UT")  
17 S17 anxiety\* OR worry\* OR denial\* OR hopelessness\* OR avoidance\*  
18 S16 efficacy OR effectiv\*  
19 S15 PT review OR PT letter OR PT comment OR PT editorial  
20 S14 percep\* OR perceive\* OR understand\* OR understood\* OR accura\* OR comprehen\*  
21 S13 S9 NOT S12  
22 S12 S10 OR S11  
23 S11 (MH "Prognosis+")  
24 S10 prognos\* OR treatment\* OR surgery\*  
25 S9 S1 AND S8  
26 S8 S6 OR S7  
27 S7 (MH "Risk Assessment+")  
28 S6 S4 AND S5  
29 S5 score\* OR model\* OR predict\* OR tool\*  
30 S4 S2 OR S3  
31 S3 (MH "Risk+")  
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44 keyword]  
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47 6 4 or 5  
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49 8 (percep\* or perceive\* or understand\* or understood\* or accura\* or comprehen\*).mp.  
50 [mp=title, abstract, heading word, drug trade name, original title, device manufacturer,  
51 drug manufacturer, device trade name, keyword]  
52 9 (efficacy\* or effectiv\*).mp. [mp=title, abstract, heading word, drug trade name, original  
53 title, device manufacturer, drug manufacturer, device trade name, keyword]  
54 10 exp prognosis/  
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8 abstract, heading word, drug trade name, original title, device manufacturer, drug  
9 manufacturer, device trade name, keyword]  
10 15 8 or 9 or 14  
11 16 10 or 11 or 12 or 13  
12 17 exp cancer screening/  
13 18 health behaviour.mp. or exp health behavior/  
14 19 ((behaviour or behavior) and health).mp. [mp=title, abstract, heading word, drug trade  
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16 keyword]  
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18 heading word, drug trade name, original title, device manufacturer, drug manufacturer,  
19 device trade name, keyword]  
20 21 20 and 1  
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23 24 23 not 16  
24 25 limit 24 to yr="2000 -Current"  
25 26 25 not review.mp. [mp=title, abstract, heading word, drug trade name, original title,  
26 device manufacturer, drug manufacturer, device trade name, keyword]

### **PsycInfo**

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33 S19 S17 NOT (S10 OR S11 OR S12)  
34 S18 S17 NOT (S10 OR S11 OR S12)  
35 S17 S7 and (S8 or S9 or S13 or S15 or S16)  
36 S16 health AND (behaviour OR behavior)  
37 S15 S14 AND S1  
38 S14 screen\* AND (uptake OR attendance OR intention OR adherence)  
39 S13 MM "Cancer Screening"  
40 S12 (prognos\* OR treatment\* OR surgery\*) AND (S10 OR S11)  
41 S11 prognos\* OR treatment\* OR surgery\*  
42 S10 DE "Prognosis"  
43 S9 efficacy or effectiv\* or worry\* or anxiety\* or hopelessness\* or denial\*  
44 S8 percep\* OR perceive\* OR understand\* OR understood\* OR accura\* OR comprehen\*  
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47 S5 DE "Risk Assessment"  
48 S4 (S2 AND S3)  
49 S3 score\* OR model\* OR predict\* OR tool\*  
50 S2 risk\*  
51 S1 DE "Neoplasms" OR DE "Benign Neoplasms" OR DE "Breast Neoplasms" OR DE  
52 "Endocrine Neoplasms" OR DE "Leukemias" OR DE "Nervous System Neoplasms"  
53 OR DE "Terminal Cancer"  
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## Supplementary file 2. Quality assessment of included studies

Author, date	Study addressed a clearly focused issue	Randomisation	Recruitment / comparability of study groups at baseline	Blinding	Exposure measurement	Outcome measurement	Comparability of study groups during study	Follow up	Overall
Bodurtha, 2009	●	●	●	●	●	●	●	●	M-H
Bowen 2006	●	●	●	●	●	●	●	●	H
Bowen 2010	●	●	●	●	●	●	●	●	H
Davis, 2004	●	●	●	●	●	●	●	●	M
Glanz, 2013	●	●	●	●	●	●	●	●	M
Glazebrook 2006	●	●	●	●	●	●	●	●	M
Greene, 2003	●	●	●	●	●	●	●	●	L-M
Helmes, 2006	●	●	●	●	●	●	●	●	M
Holloway, 2003	●	●	●	●	●	●	●	●	M-H
Lipkus , 2006	●	●	●	●	●	●	●	●	M
Lipkus, 2001	●	●	●	●	n/a	●	●	●	M
Rimer 2002	●	●	●	●	●	●	●	●	M
Rubenstein, 2011	●	●	●	●	●	●	●	●	M
Schroy, 2011	●	●	●	●	●	●	●	●	M-H
Schroy, 2012	●	●	●	●	●	●	●	●	H
Seitz 2016	●	●	●	●	●	●	●	●	M

1	Sequist 2011	●	●	●	●	●	●	●	n/a	M
2	Sherratt 2016	●	●	●	●	●	●	●	●	H
3	Trevena 2008	●	●	●	●	●	●	●	●	M

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8 ● Low (L) ● Medium (M) ● High (H)

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# PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
<b>TITLE</b>			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
<b>ABSTRACT</b>			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	2
<b>INTRODUCTION</b>			
Rationale	3	Describe the rationale for the review in the context of what is already known.	4
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	5
<b>METHODS</b>			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	5
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	5
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	5
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Supplementary file 1
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	6
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	6
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	6
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	6/7
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	7
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., $I^2$ ) for each meta-analysis.	7





# PRISMA 2009 Checklist

Page 1 of 2

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	7
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	N/A
<b>RESULTS</b>			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	7 and Figure 1
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	Table 1 and Table 2
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	Supplementary file 2
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	8-14 and Figure 4
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	8-14 and Figure 4
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	N/A
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	N/A
<b>DISCUSSION</b>			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	14/15
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	16/17
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	15/16
<b>FUNDING</b>			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	18



# PRISMA 2009 Checklist

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doi:10.1371/journal.pmed1000097

For more information, visit: [www.prisma-statement.org](http://www.prisma-statement.org).

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# BMJ Open

## Effect of interventions incorporating personalised cancer risk information on intentions and behaviour: a systematic review and meta-analysis of randomised controlled trials

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2017-017717.R2
Article Type:	Research
Date Submitted by the Author:	20-Nov-2017
Complete List of Authors:	Usher-Smith, Juliet; The Primary Care Unit, Department of Public Health and Primary Care Silarova, Barbora; MRC Epidemiology Unit, Sharp, Stephen; University of Cambridge, MRC Epidemiology Unit Mills, Katie; The Primary Care Unit, Department of Public Health and Primary Care Griffin, Simon; The Primary Care Unit, Department of Public Health and Primary Care
<b>Primary Subject Heading</b>:	Communication
Secondary Subject Heading:	Oncology
Keywords:	ONCOLOGY, PREVENTIVE MEDICINE, PUBLIC HEALTH

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Manuscripts

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2 **Effect of interventions incorporating personalised cancer risk information on intentions**  
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4 **and behaviour: a systematic review and meta-analysis of randomised controlled trials**  
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8 Juliet A Usher-Smith<sup>1</sup>, Barbora Silarova<sup>2</sup>, Stephen J Sharp<sup>2</sup>, Katie Mills<sup>1</sup>, Simon J Griffin<sup>1</sup>  
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## ABSTRACT

**Objective** To provide a comprehensive review of the impact on intention to change health-related behaviours and health-related behaviours themselves, including screening uptake, of interventions incorporating information about cancer risk targeted at the general adult population.

**Design** A systematic review and random effects meta-analysis

**Data sources** An electronic search of Medline, EMBASE, CINAHL and PsychINFO from 01/01/2000 to 01/07/2017.

**Inclusions criteria** Randomised controlled trials of interventions including provision of a personal estimate of future cancer risk based on two or more non-genetic variables to adults recruited from the general population including at least one behavioural outcome.

**Results** We included 19 studies reporting 12 outcomes. There was significant heterogeneity in interventions and outcomes between studies. There is evidence that interventions incorporating personalised cancer risk information do not affect intention to attend or attendance at screening (Relative risk (RR) 1.00 (0.97-1.03)). There is limited evidence that they increase smoking abstinence, sun protection, adult skin self-examination and breast examination and decrease intention to tan. However, they do not increase smoking cessation, parental child skin examination or intention to protect skin. No studies assessed changes in diet, alcohol consumption or physical activity.

**Conclusions** Interventions incorporating personalised cancer risk information do not affect uptake of screening but there is limited evidence of effect on some health-related behaviours. Further research, ideally including objective measures of behaviour, is needed before cancer risk information is incorporated into routine practice for health promotion in the general population.

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**Key words:** Cancer risk, systematic review, intervention, prevention, communication, meta-analysis

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### Strengths and limitations of this study

- This systematic review is the first comprehensive review of the effect on intention and health-related behaviour of individuals in the general population of interventions delivered across multiple settings which incorporate personalised information about cancer risk.
- The use of a broad search strategy across multiple databases enabled us to identify 19 randomised controlled trials reporting the impact of interventions incorporating personalised cancer risk information on 12 outcomes.
- However, there was large heterogeneity across the studies, including the content of interventions and the outcome measures. This meant it was only possible to meta-analyse one outcome, attendance at screening, and in many studies separating the effect of the risk information alone from additional elements of the interventions was not possible.

## INTRODUCTION

In 2006 the US National Cancer Institute recognised risk prediction models as an ‘area of extraordinary opportunity’<sup>1</sup>. Since then an increasing number of risk prediction models have been developed. Such models can facilitate a personalised approach to cancer prevention and treatment and a more equitable and cost-effective distribution of finite resources by targeting screening and prevention activities at those most likely to benefit. Furthermore, being able to estimate, communicate and monitor individual risk and demonstrate the impact of lifestyle change on future risk of cancer may complement wider collective approaches to shifting population distributions of behaviour, risk factors and cancer risk.

Research has shown that many individuals have incorrect perceptions of their risk of cancer<sup>2-4</sup> and that both over- and under-estimation are associated with maladaptive health-related behaviours<sup>5</sup>. Additionally, whilst up to 40% of all cancers are attributable to lifestyle factors<sup>6</sup>, only 3% of people are aware that being overweight can increase their risk of cancer and less than a third that physical activity could help reduce risk<sup>7-10</sup>. One in seven people additionally believe that lifetime risk of cancer is unmodifiable<sup>11</sup>. Most behaviour change theories suggest that perceived risk is important alongside other constructs such as self-efficacy, response efficacy in promoting behaviour change<sup>12,13</sup>. Providing individuals with estimates of their risk of cancer alongside other behaviour change interventions may therefore help motivate behaviour change at an individual level. It may also enable individuals to make more informed decisions about uptake of screening tests for cancer. This has led to the development of an increasing number of interventions incorporating information about cancer risk being developed.



1  
2 Understanding the impact of interventions incorporating information about cancer risk on  
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4 behaviour and intention to change behaviour before they are introduced into routine practice is  
5  
6 important. Previous systematic reviews in this area have focused only on trials in primary  
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8 care<sup>14</sup> or tailored information about cancer risk and screening<sup>15,16</sup>. In this review we aimed to  
9  
10 provide a comprehensive synthesis of the impact of interventions incorporating personalised  
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12 information about cancer risk on intention to change health-related behaviours and health-  
13  
14 related behaviours within the general adult population.  
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16

## 17 18 19 **METHODS**

20  
21 We performed a systematic literature review following an a priori established study protocol  
22  
23 (available on request). Reporting followed the PRISMA statement<sup>17</sup>.  
24  
25

### 26 27 28 **Search strategy**

29  
30 We performed an electronic literature search of Medline, EMBASE, CINAHL and PsychINFO  
31  
32 from January 2000 until July 2017 with no language limits using a combination of subject  
33  
34 headings and free text incorporating ‘cancer’, ‘risk/risk factor/risk assessment’ and  
35  
36 ‘prediction/model/score/tool’ (see Supplementary file 1 for the complete search strategies).  
37  
38 We then extended the search by manually screening the reference lists of all included papers.  
39  
40 We chose to begin the search in 2000 as the previous review of tailored information about  
41  
42 cancer risk and screening had noted that computer delivered interventions, as would be  
43  
44 required for calculating risk scores, were only described in publications from 2000 onwards<sup>15</sup>.  
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### 50 51 **Study selection**

52  
53 We included studies if they were randomised controlled trials (RCTs) published as a primary  
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55 research paper in a peer-reviewed journal, included adults with no previous history of cancer  
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2 and included provision to individuals of a personal estimate of future cancer risk based on two  
3  
4 or more non-genetic variables and reported at least one behavioural outcome. In order to focus  
5  
6 on the provision of personalised cancer risk to the general population, we excluded studies  
7  
8 which had recruited participants on the basis of a personal or family history of cancer or  
9  
10 following referral to specialist cancer risk services. Vignette, before-and-after studies without a  
11  
12 control group, cross-sectional, longitudinal and qualitative studies were also excluded along  
13  
14 with conference abstracts, editorials, commentaries and letters.  
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17  
18  
19 Two reviewers (JUS and BS) each screened half of the titles and abstracts to exclude papers  
20  
21 that were clearly not relevant. A third reviewer (SG) independently assessed a random  
22  
23 selection of 5% of the papers screened by each of the first reviewers. The full text was  
24  
25 examined if a definite decision to exclude could not be made based on title and abstract alone.  
26  
27 Two reviewers (JUS and BS) independently assessed all full-text papers. We discussed papers  
28  
29 for which it was unclear whether or not the inclusion criteria were met at consensus meetings  
30  
31 with a third reviewer (SG). Papers written in languages other than English were translated into  
32  
33 English for assessment and subsequent data extraction.  
34  
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38

### 39 **Data extraction**

40  
41 Two researchers (JUS+BS/KM) independently extracted data from studies included in the  
42  
43 review using a standardized data abstraction form to reduce bias. The data extracted included:  
44  
45 (1) Study characteristics (cancer type, study design, study setting, duration of follow-up); (2)  
46  
47 selection of participants (inclusion criteria, method of recruitment/randomisation); (3)  
48  
49 participant characteristics (age, level of cancer risk, sample size); (4) the intervention (risk tool  
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51 used, method and format of risk communication, additional information or follow-up  
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53 provided), and (4) measured outcome(s). Reviewers were not blinded to publication details.  
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### Quality assessment

We conducted quality assessment at the same time as data extraction using a checklist based on the Critical Appraisal Skills Programme (CASP) guidelines<sup>18</sup> as an initial framework. This includes eight questions concerning whether the study addressed a clearly focused issue, the method of recruitment and randomisation, whether blinding was used, the measurement of the exposure and outcome, the comparability of the study groups and the follow-up. Each study was then classified as high, medium or low quality. No studies were excluded based on quality alone.

### Data synthesis and statistical analysis

For analysis, we grouped the measured outcomes into those relating to: 1) preferences or intention to attend cancer screening; 2) cancer screening uptake; 3) intention or motivation to change health-related behaviour; and 4) change in health-related behaviour. It was only possible to pool results for screening attendance. For this we used random effects meta-analysis<sup>19</sup> and the 'metan' package in Stata. We present intervention effects as relative risk (RR) rather than odds ratios (OR) to avoid overestimating the risk<sup>20</sup>. We estimated the heterogeneity between studies using the  $I^2$  statistic. All analyses were conducted using statistical software package Stata/SE version 12.

## RESULTS

After duplicates were removed, the search identified 38,906 papers. Of these, 35,604 were excluded at title and abstract level and a further 183 after full-text assessment. After title and abstract screening by the first reviewers (JUS and BS), no additional papers met the inclusion criteria in the random 5% screened by the second reviewer (SG). The most common reasons

1  
2 for exclusion at full-text level were that the papers did not include provision of a personal risk  
3  
4 estimate ( $n=62$ ), did not include any data on predefined outcomes ( $n=37$ ), were conference  
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6 abstracts ( $n=20$ ), or were not primary research ( $n=16$ ) (Figure 1). Five further papers were  
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8 identified through citation searching, giving 19 studies included in the analysis.  
9

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12  
13 A summary of the participants and setting of those 19 studies is shown in Table 1. With the  
14  
15 exception of three studies conducted in the UK<sup>21-23</sup>, all studies took place in the USA. Most  
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17 recruited participants from those attending primary care clinics ( $n=3$ ), or from lists of  
18  
19 potentially eligible individuals from electronic medical records ( $n=7$ ), telephone services  
20  
21 ( $n=1$ ), insurance records ( $n=1$ ) or survey companies ( $n=1$ ). Two recruited through schools,  
22  
23 community centres and universities, one from those calling a cancer information service and  
24  
25 three used public advertisements.  
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30  
31 In eight studies personalised information was provided about risk of breast cancer, in five  
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33 about risk of colorectal cancer, in three risk of skin cancer, one lung cancer, one cervical  
34  
35 cancer and one multiple cancers. Further details of the risk models used to calculate the risk  
36  
37 estimate provided to participants and the format of the intervention(s) are given in Table 2. All  
38  
39 eight studies providing personalised information about breast cancer risk used the Gail risk  
40  
41 model<sup>24</sup>. This was the first risk model developed for breast cancer and includes age, age at  
42  
43 menarche, age at first live birth, number of previous biopsies, number of biopsies showing  
44  
45 atypical hyperplasia, and number of first-degree relatives with breast cancer. Where details  
46  
47 were given ( $n=3$ ), all studies on colorectal cancer used the Harvard Cancer Risk tool<sup>25</sup> which  
48  
49 includes family history, height and weight, alcohol consumption, vegetable and red meat  
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51 consumption, physical activity, screening history, a history of inflammatory bowel disease, and  
52  
53 use of aspirin, folate and female hormones. Other risk models used were the Liverpool Lung  
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2 Project model<sup>26</sup>, Family Healthware tool<sup>27</sup>, Wilkinson score for cervical cancer<sup>28</sup> and the brief  
3  
4 skin cancer risk assessment tool (BRAT)<sup>29</sup> adapted for children. Quality assessment for each of  
5  
6 study is provided in Supplementary file 2. Seven were assessed as high or medium/high  
7  
8 quality, 11 as medium quality and one as medium/low.  
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13 Overall findings and evidence synthesis along with the number and quality of studies  
14  
15 addressing each outcome are summarised in Table 3.  
16

### 17 18 19 **Preferences and intentions for screening**

#### 20 21 *Preferences for screening*

22  
23 Two RCTs reported participants' views about screening. In the cluster-randomised trial by  
24  
25 Holloway *et al.*<sup>21</sup> participants who received a 10 minute counselling session including  
26  
27 information about relative and absolute risks of cervical cancer integrated within a smear test  
28  
29 appointment were significantly less likely to state a preference for the next interval for cervical  
30  
31 screening to be 12 months or less than those who received usual care (OR: 0.51 (95%CI: 0.41-  
32  
33 0.64)). The second study by Lipkus *et al.*<sup>30</sup> reported attitudinal ambivalence towards faecal  
34  
35 occult blood test (FOBT) screening measured by their agreement with three Likert-style items  
36  
37 stating that they had "mixed feelings", felt "torn" and had "conflicting thoughts" about whether  
38  
39 to get screened for CRC using an FOBT. Participants who received personalised estimates of  
40  
41 either absolute or absolute plus comparative risk alongside written information about CRC  
42  
43 screening had significantly lower ambivalence than those who received the same written  
44  
45 information without tailored CRC risk information (p<0.05).  
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#### 52 *Intention to attend cancer screening*

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2 Eight studies assessed intentions to attend cancer screening: five for mammography and four  
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4 for CRC screening. Five showed no effect of risk information, three in which the only  
5  
6 substantial difference between the intervention and control groups was the provision of a risk  
7  
8 estimate<sup>31–33</sup>. Bodurtha *et al.*<sup>31</sup> found no significant differences at 18 months between those  
9  
10 randomised to receive either printed sheets with their 5-year and lifetime estimates of breast  
11  
12 cancer risk alongside information addressing barriers to mammography, breast cancer  
13  
14 seriousness and benefits of yearly mammography, or general information about breast cancer  
15  
16 prevention practices not tailored to their risk level (OR after adjusting for baseline intentions  
17  
18 and recruitment site: 0.97 (95%CI: 0.70 to 1.33)). Davis *et al.*<sup>34</sup> reported that women who  
19  
20 received a brief intervention over the telephone including information about lifetime risk of  
21  
22 cancer and screening recommendations were no more likely at one month to report being in the  
23  
24 maintenance stage (having had one mammogram in the past two years and two or more in the  
25  
26 past four years and planning to get another on schedule) than the control group who received  
27  
28 no intervention (67% in the intervention group compared to 68% in the control group). Helmes  
29  
30 *et al.*<sup>35</sup> reported changes in a single breast health intentions measure which included intention  
31  
32 to have mammography, clinical breast examination, and breast self-examination. They found  
33  
34 no significant differences at baseline (p=0.23) or three month follow-up (p=0.46) between  
35  
36 women who received estimates of their lifetime risk of breast cancer along with information  
37  
38 about breast awareness either face-to-face or over the telephone and a control group who  
39  
40 received no intervention. Schroy *et al.*<sup>32</sup> randomised participants to complete an interactive 20-  
41  
42 30 minutes computer-based decision aid which either did or did not include a personalised risk  
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44 assessment. There was no difference between groups on a five-point scale of how sure they  
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46 were that they would schedule a CRC screening test (mean scores 4.3 (standard deviation (SD):  
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48 1.0) for both groups). Trevena *et al.*<sup>33</sup> similarly reported no effect on intention to have CRC  
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50 screening of a 20-page decision aid including information about baseline risk and absolute  
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2 reduction in CRC mortality with screening, compared to a 3-page booklet with information and  
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4 recommendations about screening.  
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7  
8 The two studies reporting an effect were by Lipkus *et al.*<sup>30</sup> and Seitz *et al.*<sup>36</sup>. In Lipkus *et al.*  
9  
10 intention to complete an FOBT that would be given to them within the following month was  
11  
12 measured on a seven-point Likert scale. The intentions reported by participants who received  
13  
14 absolute risk (mean 3.65,  $n=40$ ) or absolute plus either low (mean 6.43,  $n=38$ ) or high (mean  
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16 6.65,  $n=39$ ) comparative risk information were statistically significantly higher ( $p<0.05$ ) than  
17  
18 those participants in the control group who were provided with the same written information  
19  
20 but without risk estimates (mean 2.21,  $n=43$ ). The mean intention reported by the group which  
21  
22 received the comparative risk was also significantly higher than for the absolute risk only  
23  
24 group. In Seitz *et al.* women were separated into those with an estimated 10-year breast cancer  
25  
26 risk above or below 1.5%. Intention to wait until age 50 before undergoing a mammogram was  
27  
28 measured for those with a risk  $<1.5\%$  and intention to start or continue to undergo  
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30 mammograms in their 40s for those with a risk  $\geq 1.5$ . In the low risk group, all risk-based  
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32 intervention conditions resulted in a significant increase in the percentage of women planning  
33  
34 to wait to age 50. However, in the high risk group no such significant difference was seen.  
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41 The eighth study by Lipkus *et al.*<sup>37</sup> reported the difference in intentions to get a mammogram  
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43 between one group that received a one-page handout including their estimated absolute risk  
44  
45 and another group that received the same handout plus information concerning how their risk  
46  
47 compared to a woman of their age and race at the lowest level of risk. Immediately after the  
48  
49 provision of risk information, overall 2.5%, 67.8%, and 24.8% reported that the risk  
50  
51 information lowered, did not affect, or increased their intentions to undergo a mammogram  
52  
53 respectively, with no differences between the groups.  
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### **Attendance at screening**

Twelve RCTs reported attendance at screening: six for mammography<sup>31,34,38-41</sup>; five for colorectal cancer<sup>30,32,33,38,42</sup>; and one for cervical cancer<sup>21</sup>. Except for one high quality RCT in which the intervention group received information sheets including general information on breast cancer risk alongside personalised risk information and telephone counselling and the offer for more intensive group or genetic counselling<sup>41</sup>, all showed no effect of the risk-based interventions as shown in the meta-analysis (Figure 2) with a combined RR of 1.02 (95%CI: 0.98-1.03, I<sup>2</sup>: 61.6%).

### **Intention to change health-related behaviours**

#### *Intention to tan or protect skin*

One RCT by Greene and Brinn measured intention to tan on a six-item Likert-type scale and intention to protect skin using a three-item scale<sup>43</sup>. Participants who completed a self-assessment risk score alongside receiving generic information about tanning, tanning beds and sun exposure reported significantly decreased intentions to use tanning beds than those receiving the same generic information alone (2.68,  $n=70$  compared to 3.19,  $n=71$ ,  $p<0.05$ ). In contrast there were no significant differences in intentions to protect skin (2.38,  $n=70$  compared to 2.49,  $n=71$ ,  $p>0.05$ ).

### **Change in health-related behaviours**

#### *Smoking status*

One high quality RCT<sup>23</sup> reported the impact of risk information on smoking status. Receiving a personalised risk estimate in addition to a generic leaflet did not predict self-report smoking



1  
2 status at six months in current smokers ( $p=0.66$ ) but was associated with an increased odds of  
3  
4 remaining a former smoker in those who had recently quit (OR 1.91 (95%CI 1.03-3.55)).  
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### 7 8 *Sun exposure and sun protection habits*

9  
10 Two RCTs<sup>22,44</sup> measured sun protection habits by survey completion at baseline and follow up.  
11  
12 One by Glanz *et al.* compared the effect on childhood sun exposure and sun protection habits  
13  
14 of three mailings with personalised risk feedback, interactive skin cancer education materials  
15  
16 and a family fun guide to a single mailing of standardised skin cancer information<sup>44</sup>. The other  
17  
18 by Glazebrooke *et al.* compared usual care with a self-directed computer program including  
19  
20 individualised feedback of risk alongside sections on skin protection, how to detect melanoma,  
21  
22 dangers of sun exposure, how to check skin and how to reduce risk<sup>22</sup>. Both showed increases  
23  
24 in overall sun protection habits (increase in sun protection habits index 0.19 in the intervention  
25  
26 group compared to 0.14,  $p=0.02$ <sup>44</sup> and mean difference in skin protective behaviour score  
27  
28 between intervention and control at six month follow-up 0.33 (95% CI 0.09, 0.57)<sup>22</sup>) with  
29  
30 variable results for individual aspects including wearing a sun hat, wearing a shirt, wearing  
31  
32 sunglasses, use of sun cream, number of sunburns, staying in the shade, and sun exposure  
33  
34 during weekdays and weekends.  
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### 41 *Tanning bed usage*

42  
43 The RCT by Greene and Brinn<sup>43</sup> measured change in tanning behaviour and tanning bed usage.  
44  
45 Participants who completed the self-assessment risk score reported lower rates of tanning bed  
46  
47 usage in the previous month at follow-up (2.18,  $n=70$  compared to 3.76,  $n=71$ ,  $p<0.05$ ) but no  
48  
49 difference in change in tanning behaviour from pre- to post-intervention (-1.25,  $n=70$   
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51 compared to -2.08,  $n=71$ ,  $p>0.05$ ).  
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### *Self/parent skin examination*

The two RCTs by Glanz et al. and Glazebrooke et al., measured rates of skin examination in adults<sup>22</sup> or parents and children<sup>44</sup>. Both showed statistically significant increases among adults and parents receiving personalised risk information ( $p<0.05$ ) while the increase in parents examining their children was not statistically significant ( $p=0.06$ ).

### *Clinical breast examination and breast self-examination*

Three RCTs<sup>31,40,41</sup> measured rates of clinical breast examination and/or breast self-examination following provision of risk information. In the RCT by Bodurtha *et al.*, no significant differences were seen between those randomised to receive printed sheets including estimates of 5-year and lifetime risk of breast cancer alongside information addressing barriers to mammography, breast cancer seriousness and benefits of yearly mammography and those receiving general information about breast cancer prevention practices not tailored to their risk level for either frequency of clinical breast examination (crude rates: 91.4% vs 91.0%; adjusted OR: 1.00 (95%CI: 0.60 to 1.66)) or breast self-examination (crude rates: 56.8% vs 57.6%; adjusted OR: 0.95 (95%CI: 0.67 to 1.33)<sup>31</sup>. The other two studies, both by Bowen *et al.*, found significantly ( $p<0.01$ ) greater increases in the proportion reporting performing breast self-examination in the intervention groups (35% to 52% and 36% to 62%) compared with controls (33% to 36% and 38% to 40%)<sup>40,41</sup>. However, both these studies compared intensive interventions (four weekly 2-hour sessions led by a health counsellor<sup>40</sup> or information sheets plus telephone counselling and the offer of more intensive group or genetic counselling<sup>41</sup>) with delayed intervention.

## **DISCUSSION**

This systematic review is, to our knowledge, the first review of the impact of interventions

1  
2 delivered across multiple settings which incorporate personalised information about cancer risk  
3  
4 on intention to change health-related behaviour and health-related behaviours themselves in the  
5  
6 general population. The findings show that such interventions do not affect intention to attend  
7  
8 or attendance at screening. There is limited evidence that they increase smoking abstinence,  
9  
10 sun protection, adult skin self-examination and breast examination and decrease intention to  
11  
12 tan. However, this was not seen for smoking cessation, parental child skin examination or  
13  
14 intention to protect skin. There is a notable absence of studies assessing the impact on diet,  
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16 physical activity and alcohol consumption with only one reporting smoking status and none  
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18 including objective measures of behaviour.  
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24 Our finding that interventions incorporating personalised information about cancer risk had no  
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26 effect on intention to attend or attendance at screening is consistent with a previous Cochrane  
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28 review in which personalised risk communication had little effect on the uptake of screening  
29  
30 tests (fixed-effect OR 0.95 (95% CI 0.78 to 1.15))<sup>16</sup>. However, as in that review, there was  
31  
32 evidence of increased concordance between screening preferences and recommendations and  
33  
34 decreased ambivalence. This supports the suggestion made in that review that personalised risk  
35  
36 information might be useful for shared and informed decision making. For example, in surveys  
37  
38 of participants about their knowledge and values for cancer screening decisions and decision-  
39  
40 making processes, only 21% report feeling extremely well informed<sup>45</sup> and the majority  
41  
42 overestimate lifetime risk of cancer incidence and mortality<sup>45,46</sup>. While providing individuals  
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44 with information about their estimated cancer risk may therefore not influence overall rates of  
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46 screening it may contribute to the decision to take up screening or not at an individual level and  
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48 support shared decision making.  
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54 The absence of significant effects on health-related behaviours is also consistent with research  
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1  
2 in other disease areas, such as cardiovascular disease, where systematic reviews have found  
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4 only few studies reporting behaviour change and no significant effects on lifestyle<sup>47-49</sup>. This is  
5  
6 perhaps not surprising given that behaviour change is influenced by many other factors,  
7  
8 including health beliefs, social context, the environment, and personal attributes such as time  
9  
10 orientation<sup>12,13</sup>. However, there was no evidence that interventions that include information  
11  
12 about cancer risk result in harm through false reassurance and the adoption of unhealthy  
13  
14 behaviours. This is important as on average many of the general population overestimate their  
15  
16 own risk of cancer<sup>30,35,40,50-52</sup> and so if information about cancer risk were routinely provided  
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18 within clinical practice large numbers would be receiving an estimate lower than their prior  
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20 perceptions.  
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26 The main strengths of this review are the systematic search of multiple electronic databases and  
27  
28 the broad inclusion criteria. This allowed us to include studies that assess the impact of  
29  
30 interventions incorporating personalised cancer risk information on multiple behavioural  
31  
32 outcomes. However, from nearly 40,000 titles and abstracts, we only included 14 with an  
33  
34 additional 5 found through citation searching. This highlights the challenge in identifying  
35  
36 studies in this area in which the primary purpose may not be related to the provision of  
37  
38 personalised risk information. There was also significant heterogeneity in the outcome  
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40 measures included, duration of follow-up and method of recruitment across the included  
41  
42 studies. For all outcomes except attendance at screening there were either too few studies to  
43  
44 meaningfully pool results or each study used different non-comparable measures. Even for  
45  
46 attendance at screening for which meta-analysis was possible, we were only able to pool crude  
47  
48 estimates and the included studies addressed screening for breast, bowel and cervical cancer.  
49  
50 While it is possible that the impact on screening attendance might be different across the  
51  
52 different cancer sites because of the nature of the tests involved, the finding that only one study  
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1  
2 of mammography showed an effect of interventions incorporating personalised cancer risk  
3  
4 information suggests that this is unlikely to be the case. The duration of follow-up also varied  
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6 from 1 to 18 months. However, the studies with shorter follow-up were those with intention as  
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8 the outcome measures and, of the 10 studies reporting health-related behaviours, five had a  
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10 follow-up period of a year or more and three a period of six months. It is therefore unlikely that  
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12 the studies as a whole were too short to detect changes in behaviour or reflected only  
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14 immediate un-sustained changes.  
15  
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18  
19 A further limitation is that many of the interventions consisted of provision of personalised risk  
20  
21 information alongside a range of additional information, either written or delivered in person or  
22  
23 in groups. Separating the effect of the risk information from those additional elements of the  
24  
25 interventions was therefore not possible. However, we chose not to exclude these studies from  
26  
27 this review because it is unlikely that personalised risk information would be incorporated into  
28  
29 routine practice in isolation and, if anything, including them would overestimate the effect of  
30  
31 the personalised risk information. It is also possible that the findings do not reflect the potential  
32  
33 impact of interventions incorporating personalised information about cancer risk on the general  
34  
35 population as a whole: half of the included studies focused on female cancers and so only  
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37 recruited women and all were subject to recruitment bias with the participants who agreed to  
38  
39 take part potentially more interested in their cancer risk or more healthy, resulting in a bias in  
40  
41 either direction.  
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46  
47 In addition to these specific limitations of our review, the findings also suggest a number of  
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49 areas for future research. In particular, the absence of studies assessing the impact on diet,  
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51 physical activity and alcohol consumption, and only one study reporting smoking cessation,  
52  
53 demonstrate the need for trials assessing change in these behaviours, preferably measured  
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1  
2 objectively, including measures of other theory based determinants of behaviour change (for  
3  
4 example, self-efficacy). Only with such data will we be able to assess whether such  
5  
6 individualised approaches have a place alongside population-wide prevention strategies.  
7  
8  
9

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## 18 **Contributors**

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50 account of the study being reported; that no important aspects of the study have been omitted;  
51 and that any discrepancies from the study as planned (and, if relevant, registered) have been  
52 explained.  
53  
54  
55

## FIGURE LEGENDS

Figure 1. PRISMA flow diagram

Figure 2. Relative risk for adherence to recommended screening post intervention. CRC – colorectal cancer; FOBT – faecal occult blood test; AR – absolute risk; CR – comparative risk

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**Table 1.** Details of the setting and key outcomes of the included studies

Author, year	Cancer site(s)	Follow-up	Setting and participants	Risk level / co-morbidities	Outcome(s)	Quality*
Bodurtha 2009	Breast	18 months	899 women with no history of breast cancer recruited from waiting rooms of four women's health clinics	Not given	Mammography, clinical breast examinations, breast self-examination, mammography intentions	M-H
Bowen 2006	Breast	6 and 24 months	150 sexual minority women recruited via public advertisements	Mean Gail lifetime risk 12%	Breast self-examination, breast cancer screening	H
Bowen 2010	Breast	12 months	1,366 women recruited via purchased lists of telephone numbers with no previous diagnosis of breast cancer	Mean Gail lifetime risk 12%	Breast self-examination, mammography	
Davis, 2004	Breast	1 month	392 women with no history cancer calling the Cancer Information Service	27% 2-6% lifetime risk; 32% 6-9% lifetime risk; 41% 9-46% lifetime risk	Adherence to breast cancer screening, intention for breast cancer screening	M
Glanz 2013	Skin	16 weeks	Convenience sample of 1047 parents not currently being treated for skin cancer recruited through schools and community centres	38% high risk	Sun protection habits, sun exposure, skin examination by parents	M
Glazebrook 2006	Skin	6 months	589 recruited from 10 primary care practices from a convenience sample of appointments	Not given	Sun protection habits	M
Greene 2003	Skin	3-4 weeks	141 undergraduates at one university who received extra credit for participation	Not given	Intention to tan, actual tan bed usage	L-M
Helmes, 2006	Breast	3 months	Random sample of 340 members of state healthcare system with no history of breast/ovarian cancer or testing for cancer risk	Mean 9.5% (3.2) lifetime risk	Intention to have mammogram and clinical breast examination, intention to do breast self-examination	M
Holloway, 2003	Cervical	0, 4 years	1890 women attending routine cervical smear test at one of 29 GP practices	78-80% very low risk; 20-22% low risk	Preference for future screening interval, actual screening behaviour	M-H
Lipkus 2006	Colorectal	0	160 members of general public with no history of CRC or screening for CRC recruited through newspaper advertisements	Not given	Ambivalence, intention to screen using a FOBT, actual FOBT screening rates	M
Lipkus, 2001	Breast	0	121 members of general public recruited through newspaper advertisements	Mean 10 year risk 2.65% (SD 1.13)	Mammography screening and intentions	M
Rimer 2002	Breast	1 and 2 years	752 women aged 40-44 and 50-54 enrolled in a personal care plan	Mean 10 year risk 2.7%	Mammography	M
Rubenstein 2011	Breast, ovarian, colon	6 months	3786 patients from primary care clinic records with no history of colon, breast or ovarian cancer invited by mail following record review	34% moderate or strong risk of $\geq 1$ of the cancers	CRC screening, mammography	M

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3	Schroy, 2011	Colorectal	0	666 patients due for bowel screening identified from monthly audits of one hospital's electronic medical record	Average	Preferences, satisfaction with the decision-making process, screening intentions, and test concordance	M-H
4							
5	Schroy, 2012	Colorectal	0, 1, 3, 6 and 12 months	825 patients due for bowel screening identified from monthly audits of one hospital's electronic medical record	Average	Completion of a CRC screening test	H
6							
7	Seitz 2016	Breast	0	2,918 women aged 35-49 with no history of breast cancer or a genetic mutation in BRCA1 or BRCA2 recruited through a survey company	42% 10 year risk <1.5% (mean 1.08 SD 0.01); 58% 10 year risk ≥1.5% (mean 2.53 SD 0.04)	Mammography intentions	M
8							
9	Sequist 2012	Colorectal	1 and 4 months	1,103 patients from 14 ambulatory health centres who were overdue for colorectal cancer screening	Average	CRC screening	M
10							
11	Sherratt 2016	Lung	6 months	297 current and 216 recent former smokers aged 18-60 without a history of lung cancer and attending smoking cessation services	Not given	Smoking status	H
12							
13	Trevena 2008	Colorectal	1 month	314 patients recruited from 6 primary care practices without a history of colorectal cancer	Not given	Screening intentions, CRC screening	M
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RCT – randomised controlled trial; CRC – colorectal cancer; CT computerised tomography; FOBT – faecal occult blood test

\* L – low, M – medium, H - high

**Table 2.** Details of the risk-based interventions in each of the included studies

Author, year	Risk tool	Intervention group(s)	Comparison (where applicable)	Format of risk
Bodurtha 2009	Gail model (5 year and lifetime)	Information sheets with risk level and handouts addressing traditional constructs of Health Belief Model including barriers to mammography, breast cancer seriousness, individual risk for breast cancer, and benefits of yearly mammography	General information about breast cancer prevention practices, including mammography	Usual (<15%), Moderate (15-30%) or Strong (>30%)
Bowen 2006	Gail model (5 year, 10 year and at age 79)	Four weekly 2-hour sessions led by a health counsellor focusing on risk assessment and education, screening, stress management and social support	Delayed intervention	No details given
Bowen 2010	Gail model (lifetime)	Information sheets with general information on breast cancer risk and personalised risk information plus telephone counselling and offer for more intensive group or genetic counselling	Delayed intervention	Bar graph of absolute lifetime risk along with age-appropriate estimates for the "average risk" woman
Davis, 2004	BRCA tool (updated version of Gail model) (lifetime)	10min brief intervention designed to increase accuracy of perceived risk including results of risk assessment and screening recommendations tailored to participant's stage of adoption of mammography and follow up written information	No intervention	Verbal over the telephone. No additional details given.
Glanz 2013	Children's BRAT	Three mailings with personalised risk feedback, interactive skin cancer education materials, a family fun guide and suggestions for overcoming barriers and reminders to engage in preventive practices	Single mailing of standardised skin cancer information	No details given
Glazebrooke 2006	No details given	Self-directed computer program including sections on skin protection, how to detect melanoma, dangers of sun exposure, how to check skin, how to reduce risk and individualized feedback of risk	Usual care	Comparative risk
Greene 2003	Relative risk adapted from "ADD Wants to Convert"	Self-assessment of risk alongside generic messages about tanning, tanning beds and sun exposure	Generic messages about tanning, tanning beds and sun exposure	Numerical scale from 1-36
Helmes, 2006	Gail model (lifetime)	Face-to-face or telephone intervention consisting of 8 items: 1) a personal risk sheet ; 2) a personal computer-drawn pedigree; 3) a 23 page participant booklet; 4) Breast self-examination brochure; 5) Pap smear and mammography	No intervention	Bar charts of absolute % risk with numerical % alongside for the individual, an average-risk woman, and a high-risk woman



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3			brochure; 6) BSE shower card; 7) pictures of chromosomes		
4			and gene mutations; 8) a list of community resources for		
5			breast cancer		
6	Holloway,	Wilkinson score	Brief 10 minute counselling session integrated with smear	Usual care	Comparative and absolute risk in pictures
7	2003		test appointment including relative and absolute risks and		and numbers
8			then negotiation of appropriate screening intervals		
9	Lipkus 2006	Not given	Written information about CRC, CRC screening methods	Written information about	Narrative comparative risk
10			and CRC risk factors plus either 1) tailored CRC risk factor	CRC, CRC screening	
11			information or 2) tailored CRC risk factor information plus	methods, and CRC risk	
12			information on whether their total number of CRC risk	factors	
13			factors was greater or not than average		
14	Lipkus, 2001	Gail model (10	1 page handout describing the Gail model plus absolute risk	As for intervention group	Absolute risk +/- risk of a woman at the
15		year)	alone	plus how their risk compared	lowest level of risk as percentages in a pie
16				to a woman of their age and	chart
17				race at the lowest level of	
18				risk	
19	Rimer 2002	Gail model (10 year	Tailored print booklet and brief tailored newspaper plus	Usual care (postcard	Absolute risk as a percentage
20		and lifetime)	personalized risk	reminder)	
21	Rubenstein	Family Healthcare	Written personalized risk assessment and tailored prevention	Written generalized	Qualitative risk - weak, moderate or strong
22	2011	tool	messages	prevention messages	familial risk
23	Schroy, 2011	Harvard cancer risk	Interactive 20-30 min computer-based decision aid plus	Interactive 20-30 min	Thermograph, indicating where the
24		model (10 year)	personalized risk assessment	computer-based decision aid	participant is along with a description e.g.
25				alone	your risk is below average
26	Schroy, 2012	Harvard cancer risk	Interactive 20-30 min computer-based decision aid plus	As for intervention but	Qualitative framing (“very much below
27		model (10 year)	personalized risk assessment followed immediately by a	without personalized risk	average risk” to “very much above average
28			meeting with their providers to discuss screening and	assessment	risk”) with accompanying suggestions for
29			identify a preferred screening strategy. Providers received		behaviour modifications that might reduce
30			written notification hand-delivered by all the patients		risk, including a strong recommendation for
31			acknowledging that they were participating in the “CRC		screening, regardless
32			decision aid study” at the time of the visit to ensure that		of risk
33			screening was discussed		
34	Seitz 2016	Gail model (10	Online risk plus basic information about mammography and	No information or the same	Absolute risk and risk of an average-risk
35		year)	national recommendations plus either 1) statements about	basic information as	age-matched women as numeric frequencies
36			women making choices 2) untailored exemplars of women	intervention group	and icon arrays
37			making choices or 3) exemplars of similar women making		
38			choices		

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Sequist 2011	Harvard cancer risk model (10 year)	Personalized electronic message highlighting their overdue screening status and providing a link to a web-based tool to assess their risk	No contact	Comparative risk on 7-point ordinal scale from very-much below average to very-much above average and in interactive graphical format
Sherratt 2016	Liverpool Lung Project model (5 year at age 70)	Personalised risk plus booklet stating the association between smoking and lung cancer and highlighting that quitting smoking was the best thing to do	As for intervention but without personalized risk assessment	Verbal and written absolute risk if continue to smoke and if stop smoking alongside icon arrays
Trevena 2008	No details given	20 page booklet including personalized risk, absolute reduction in colorectal cancer mortality with screening over the next 10 years, probability of test outcomes from screening and information about how to get screened.	3 page booklet with information and recommendations about screening	Words and 1000-face diagrams

CRC – colorectal cancer

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**Table 3. Summary of evidence on outcomes**

Outcome measure	Number of studies	Studies with significant positive effect	Studies with no effect	Best evidence synthesis
<b>Screening</b>				
Preferences for screening	2	1 medium/high quality and 1 high quality RCT	None	Evidence of positive effect
Intention to attend screening	8	1 medium quality RCT*	1 high quality, 1 medium/high quality and 4 medium quality RCTs*	Evidence of no effect
Attendance at screening	12	1 high quality RCT	2 high quality, 2 medium/high quality and 7 medium quality studies	Evidence of no effect
<b>Health-related behaviours</b>				
<b>Intention to change health-related behaviours</b>				
To tan	1	1 low/medium RCT	None	Limited evidence of positive effect
To protect skin	1	None	1 low/medium RCT	Limited evidence of no effect
<b>Health-related behaviours</b>				
Smoking cessation	1	None	1 high quality RCT	Limited evidence of no effect
Smoking abstinence	1	1 high quality RCT	None	Limited evidence of positive effect
Sun protection	2	2 medium quality RCTs		Indicative evidence of positive effect
Tanning bed usage	1	None	1 low/medium RCT	Limited evidence
Adult skin examination	2	2 medium quality RCTs	None	Indicative evidence of positive effect
Child skin examination	1	None	1 medium quality RCT	Limited evidence of no effect
Breast examination	3	2 high quality RCTs	1 medium/high RCT	Indicative evidence of positive effect
Diet	0	None	None	No evidence
Physical activity	0	None	None	No evidence
Alcohol	0	None	None	No evidence

\* 1 medium quality study reported a significant positive effect in low risk women and no effect in high risk women

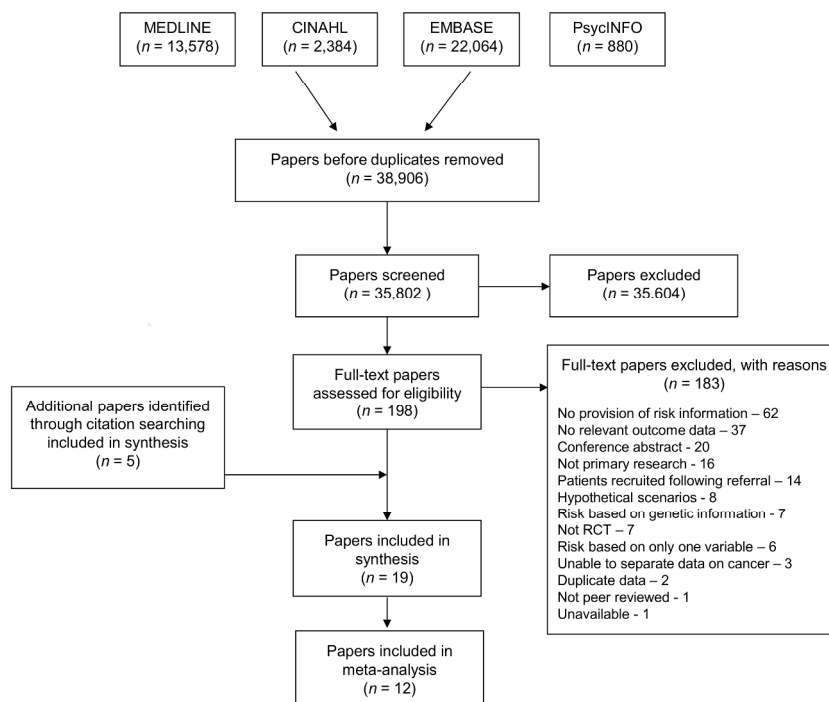


Figure 1. PRISMA flow diagram

254x190mm (300 x 300 DPI)

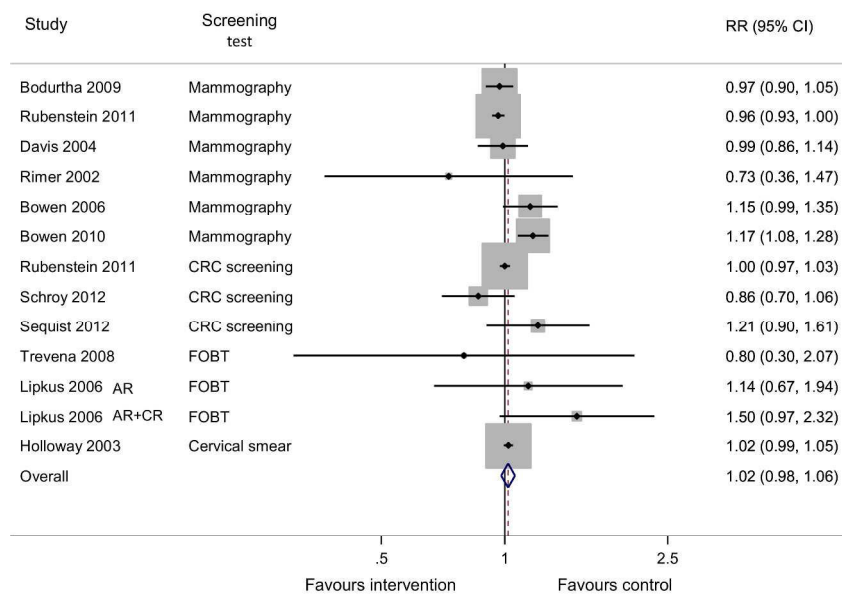


Figure 2. Relative risk for adherence to recommended screening post intervention. CRC – colorectal cancer; FOBT – faecal occult blood test; AR – absolute risk; CR – comparative risk

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3 **Supplementary file 1 – Complete search strategy**  
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5 ***Medline and Cinahl***

6 S28 S26 NOT S27  
7 S27 review  
8 S26 S24 AND S25  
9 S25 S13 NOT S15  
10 S24 S14 OR S16 OR S17 OR S21 OR S22 OR S23  
11 S23 ( behaviour OR behavior ) AND health  
12 S22 (MH "Health Behavior+") OR (MH "Risk Reduction Behavior+")  
13 S21 S18 OR S20  
14 S20 S19 AND S1  
15 S19 screen\* AND uptake OR attendance OR intention OR adherence  
16 S18 (MM "Early Detection of Cancer/UT")  
17 S17 anxiety\* OR worry\* OR denial\* OR hopelessness\* OR avoidance\*  
18 S16 efficacy OR effectiv\*  
19 S15 PT review OR PT letter OR PT comment OR PT editorial  
20 S14 percep\* OR perceive\* OR understand\* OR understood\* OR accura\* OR comprehen\*  
21 S13 S9 NOT S12  
22 S12 S10 OR S11  
23 S11 (MH "Prognosis+")  
24 S10 prognos\* OR treatment\* OR surgery\*  
25 S9 S1 AND S8  
26 S8 S6 OR S7  
27 S7 (MH "Risk Assessment+")  
28 S6 S4 AND S5  
29 S5 score\* OR model\* OR predict\* OR tool\*  
30 S4 S2 OR S3  
31 S3 (MH "Risk+")  
32 S2 risk\*  
33 S1 "cancer" OR (MH "Neoplasms+")  
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39 ***Embase***

40 1 cancer.mp. or exp neoplasm/  
41 2 exp risk/ or risk\*.mp.  
42 3 (score\* or model\* or predict\* or tool\*).mp. [mp=title, abstract, heading word, drug  
43 trade name, original title, device manufacturer, drug manufacturer, device trade name,  
44 keyword]  
45 4 2 and 3  
46 5 exp risk assessment/  
47 6 4 or 5  
48 7 1 and 6  
49 8 (percep\* or perceive\* or understand\* or understood\* or accura\* or comprehen\*).mp.  
50 [mp=title, abstract, heading word, drug trade name, original title, device manufacturer,  
51 drug manufacturer, device trade name, keyword]  
52 9 (efficacy\* or effectiv\*).mp. [mp=title, abstract, heading word, drug trade name, original  
53 title, device manufacturer, drug manufacturer, device trade name, keyword]  
54 10 exp prognosis/  
55 11 (prognos\* or treatment\* or surgery\*).mp. [mp=title, abstract, heading word, drug trade  
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57 keyword]  
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3 12 (review or letter or comment or editorial).pt.  
4 13 (radiotherapy\* or stage\* or grade\*).mp. [mp=title, abstract, heading word, drug trade  
5 name, original title, device manufacturer, drug manufacturer, device trade name,  
6 keyword]  
7 14 (anxiety\* or worry\* or fatalism\* or hopelessness\* or denial\* or avoid\*).mp. [mp=title,  
8 abstract, heading word, drug trade name, original title, device manufacturer, drug  
9 manufacturer, device trade name, keyword]  
10 15 8 or 9 or 14  
11 16 10 or 11 or 12 or 13  
12 17 exp cancer screening/  
13 18 health behaviour.mp. or exp health behavior/  
14 19 ((behaviour or behavior) and health).mp. [mp=title, abstract, heading word, drug trade  
15 name, original title, device manufacturer, drug manufacturer, device trade name,  
16 keyword]  
17 20 (screen\* and (uptake or attendance or intention or adherence)).mp. [mp=title, abstract,  
18 heading word, drug trade name, original title, device manufacturer, drug manufacturer,  
19 device trade name, keyword]  
20 21 20 and 1  
21 22 15 or 17 or 18 or 19 or 21  
22 23 22 and 7  
23 24 23 not 16  
24 25 limit 24 to yr="2000 -Current"  
25 26 25 not review.mp. [mp=title, abstract, heading word, drug trade name, original title,  
26 device manufacturer, drug manufacturer, device trade name, keyword]

### **PsycInfo**

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32 S20 S19 NOT review Limiters - Publication Year: 2000-2015  
33 S19 S17 NOT (S10 OR S11 OR S12)  
34 S18 S17 NOT (S10 OR S11 OR S12)  
35 S17 S7 and (S8 or S9 or S13 or S15 or S16)  
36 S16 health AND (behaviour OR behavior)  
37 S15 S14 AND S1  
38 S14 screen\* AND (uptake OR attendance OR intention OR adherence)  
39 S13 MM "Cancer Screening"  
40 S12 (prognos\* OR treatment\* OR surgery\*) AND (S10 OR S11)  
41 S11 prognos\* OR treatment\* OR surgery\*  
42 S10 DE "Prognosis"  
43 S9 efficacy or effectiv\* or worry\* or anxiety\* or hopelessness\* or denial\*  
44 S8 percep\* OR perceive\* OR understand\* OR understood\* OR accura\* OR comprehen\*  
45 S7 (S1 AND S6)  
46 S6 (S4 OR S5)  
47 S5 DE "Risk Assessment"  
48 S4 (S2 AND S3)  
49 S3 score\* OR model\* OR predict\* OR tool\*  
50 S2 risk\*  
51 S1 DE "Neoplasms" OR DE "Benign Neoplasms" OR DE "Breast Neoplasms" OR DE  
52 "Endocrine Neoplasms" OR DE "Leukemias" OR DE "Nervous System Neoplasms"  
53 OR DE "Terminal Cancer"  
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## Supplementary file 2. Quality assessment of included studies

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Author, date	Study addressed a clearly focused issue	Randomisation	Recruitment / comparability of study groups at baseline	Blinding	Exposure measurement	Outcome measurement	Comparability of study groups during study	Follow up	Overall
Bodurtha, 2009	●	●	●	●	●	●	●	●	M-H
Bowen 2006	●	●	●	●	●	●	●	●	H
Bowen 2010	●	●	●	●	●	●	●	●	H
Davis, 2004	●	●	●	●	●	●	●	●	M
Glanz, 2013	●	●	●	●	●	●	●	●	M
Glazebrook 2006	●	●	●	●	●	●	●	●	M
Greene, 2003	●	●	●	●	●	●	●	●	L-M
Helmes, 2006	●	●	●	●	●	●	●	●	M
Holloway, 2003	●	●	●	●	●	●	●	●	M-H
Lipkus , 2006	●	●	●	●	●	●	●	●	M
Lipkus, 2001	●	●	●	●	n/a	●	●	●	M
Rimer 2002	●	●	●	●	●	●	●	●	M
Rubenstein, 2011	●	●	●	●	●	●	●	●	M
Schroy, 2011	●	●	●	●	●	●	●	●	M-H
Schroy, 2012	●	●	●	●	●	●	●	●	H
Seitz 2016	●	●	●	●	●	●	●	●	M



1	Sequist 2011	●	●	●	●	●	●	●	n/a	M
2	Sherratt 2016	●	●	●	●	●	●	●	●	H
3	Trevena 2008	●	●	●	●	●	●	●	●	M

● Low (L) ● Medium (M) ● High (H)

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# PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
<b>TITLE</b>			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
<b>ABSTRACT</b>			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	2
<b>INTRODUCTION</b>			
Rationale	3	Describe the rationale for the review in the context of what is already known.	4
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	5
<b>METHODS</b>			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	5
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	5
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	5
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Supplementary file 1
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	6
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	6
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	6
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	6/7
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	7
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., $I^2$ ) for each meta-analysis.	7



# PRISMA 2009 Checklist

Page 1 of 2

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	7
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	N/A
<b>RESULTS</b>			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	7 and Figure 1
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	Table 1 and Table 2
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	Supplementary file 2
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	8-14 and Figure 4
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	8-14 and Figure 4
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	N/A
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	N/A
<b>DISCUSSION</b>			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	14/15
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	16/17
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	15/16
<b>FUNDING</b>			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	18



# PRISMA 2009 Checklist

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