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Interventions to Promote Cancer Awareness and Early Presentation: Systematic Review

Running title: Systematic review of cancer awareness interventions

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ABSTRACT

Low cancer awareness contributes to delay in presentation for cancer symptoms and may lead to delay in cancer diagnosis. The aim of this study was to review the evidence for the effectiveness of interventions to raise cancer awareness and promote early presentation in cancer to inform policy and future research. We searched bibliographic databases and reference lists for randomised controlled trials of interventions delivered to individuals, and controlled or uncontrolled studies of interventions delivered to communities. We found some evidence that interventions delivered to individuals modestly increase cancer awareness in the short term and insufficient evidence that they promote early presentation. We found limited evidence that public education campaigns reduce stage at presentation of breast cancer, malignant melanoma and retinoblastoma.

Key words: Cancer awareness; Cancer knowledge; Delay; Complex interventions;

Early presentation; Health service utilisation

INTRODUCTION

Late stage at diagnosis is a major factor accounting for survival differences between European countries for several cancers (Gatta *et al*, 2000; Sant *et al*, 2003; Sant *et al,* 2007). For some cancers, for example, breast, late stage at diagnosis has been shown to contribute to the difference in survival between rich and poor (Downing *et al*, 2007) and black and white women (Jack *et al*, 2009).

Patient delay in presenting for medical help after symptom discovery is likely to contribute to late stage at diagnosis. Low cancer awareness (which may include knowledge or beliefs about cancer symptoms, risk of developing cancer, risk factors, effectiveness of treatment or effectiveness of strategies for early detection) is a risk factor for patient delay (MacDonald *et al*, 2004; Ramirez *et al*, 1999).

In 2003, the Department of Health commissioned a systematic review of evidence about factors influencing delay in cancer diagnosis. While not its main focus, it included studies examining effectiveness of interventions to reduce patient delays in cancer diagnosis (MacDonald *et al*, 2004). It concluded that there had been little research in this area but that public cancer awareness campaigns had been associated with some improvements in awareness and diagnosis of cancer but that the long-term benefits were unclear.

The lack of evidence about the effectiveness of interventions to promote cancer awareness and early presentation is hampering development of policy and local action.

The aim of this study was to examine the evidence of effectiveness of interventions to raise cancer awareness and promote early presentation with cancer symptoms to inform policy and future research.

METHODS

Search strategy

We searched the peer-reviewed literature published in English for studies examining the effectiveness of interventions to increase cancer awareness or promote early presentation. We searched the Cochrane Library; Medline; EMBASE; and PsychINFO from 2000 to November 2008 (see Appendix A for search strategy). Two reviewers identified relevant studies from titles and abstracts; a third reviewer resolved disagreements. We checked the reference lists of identified reports for further relevant studies.

Study selection criteria

We included studies examining interventions in any population except those targeting only people at high genetic risk or aiming to increase cancer awareness in health professionals exclusively. We searched for studies examining effectiveness of two types of intervention:

- Interventions delivered to identified individuals recruited to a study which attempted to collect outcome data from those individuals after the intervention, for example, a one-to-one interaction with a health professional, or a leaflet given or posted to an identified individual ('individual-level interventions');
- Interventions delivered to communities in which researchers did not control or identify which individual received the intervention, for example, media

campaigns; leaflets distributed indiscriminately at a health club; street stalls with posters and leaflets to promote early presentation ('community-level interventions').

For individual-level interventions, we searched for randomised controlled trials in which the comparator was placebo, no intervention or usual care. We excluded studies comparing two different interventions, or variants of an intervention.

For community-level interventions, we searched for controlled trials (with contemporaneous controls, randomised or non-randomised, with comparator no intervention) and uncontrolled studies that collected data on outcomes before-and-after the intervention. This was to acknowledge that evaluating community-level interventions in randomised controlled trials is difficult and that policy on implementation of these is often made on the basis of less rigorous evaluations.

We categorised each type of study by whether the outcome related to cancer awareness or early presentation. We included studies with any one of the following cancer awareness outcomes: knowledge or beliefs about cancer symptoms, what to look for when detecting a change that might be cancer, risk of cancer, cancer risk factors, effectiveness of cancer treatment if given early, or natural history or prognosis of cancer; attitudes towards early detection behaviours and help-seeking; or confidence to detect a change that might be cancer. We included studies with any one of the

following outcomes that might reflect early presentation: time from symptom discovery to presentation or diagnosis; stage of disease at diagnosis; or survival/mortality.

We excluded studies examining exclusively any of the following outcomes: knowledge of or beliefs about: nature of treatment for cancer, cancer screening, or checking behaviours (for example, checking breasts, testicles or skin); health-checking behaviour (for example, frequency of or competency in breast, testicular or skin self-examination); intentions to take up screening; or screening uptake. We excluded studies with composite outcomes including the outcomes of interest, where these were not reported separately.

We also excluded studies in which the only post-intervention outcome measure was taken on the same day the intervention was delivered (see Appendix B for summary of inclusion and exclusion criteria).

Two reviewers independently extracted data from all papers identified as potentially relevant onto a data extraction form (Appendix C). Two reviewers independently applied the inclusion criteria and a third reviewer resolved disagreements.

Quality assessment

The quality of randomised controlled trials eligible for inclusion in the review was scored using a methodology checklist developed previously by members of the review team (Goldsmith *et al*, 2006) (Appendix D provides the form used by reviewers to measure quality). Each criterion on the checklist was assessed as *well covered*, *adequately*

addressed, *poorly addressed*, *not reported* or *not applicable*. The methodological quality of each study was then rated as: ++ (all or most of the criteria have been fulfilled), + (some of the criteria have been fulfilled) or – (few or no criteria have been fulfilled). We did not formally score quality of studies of community-level interventions.

Data synthesis

We conducted non-quantitative synthesis of evidence by preparing tables summarising the results of studies for each of the main outcomes of interest.

RESULTS

The search strategy identified 2557 abstracts. Of these, 90 were identified as meeting the criteria and we obtained full text versions of these reports. We subsequently found that 42 of these were not relevant. We excluded three out of the remaining 48 reports because the outcomes did not meet the inclusion criteria. This left 35 studies of individual-level interventions and ten of community-level interventions. From the individual level interventions, we excluded 18 because outcomes were measured on the same day as the delivery of the intervention, seven because they were not randomised controlled trials and five because the studies compared interventions with other interventions, rather than no intervention or usual care (Figure 1).

Individual-level interventions

We found five randomised controlled trials of individual-level interventions examining cancer awareness outcomes and none examining early presentation outcomes.

Description of studies and interventions

The five randomised controlled trials were carried out in the UK, US and the Netherlands, and are described in Table 1. Two were cluster randomised controlled trials (Boundouki *et al*, 2004; Glazebrook *et al*, 2006). The trials focused on all cancers (de Nooijer *et al*, 2004), prostate cancer (Wilt *et al*, 2001), breast cancer (Rimer *et al*, 2002), oral cancer (Boundouki *et al*, 2004) and malignant melanoma (Glazebrook *et al*, 2006). Four of the trials examined the effectiveness of written information compared

with no written information, either sent by post (de Nooijer *et al*, 2004; Rimer *et al*, 2002; Wilt *et al*, 2001) or given out in a waiting room (Boundouki *et al*, 2004). In one trial, the written information was supplemented by telephone counselling in a third arm (Rimer *et al*, 2002). Another trial examined the additional effect of tailoring the postal information to individual knowledge and intentions in a third arm (de Nooijer *et al*, 2004). The fifth study examined the effectiveness of an interactive computer programme in general practice (Glazebrook *et al*, 2006). All trials examined knowledge outcomes but at different times after the intervention: two weeks (Wilt *et al*, 2001), three weeks (de Nooijer *et al*, 2004), eight weeks (Boundouki *et al*, 2004), six months (Glazebrook *et al*, 2006; de Nooijer *et al*, 2004) and 24 months after (Rimer *et al*, 2002). All used different measures of cancer knowledge: three used knowledge scores encompassing a range of elements of knowledge (de Nooijer *et al*, 2004; Glazebrook *et al*, 2006; Boundouki *et al*, 2004); one study examined attitudes towards paying attention to and seeking help for symptoms (de Nooijer *et al*, 2004); and two used only one or two isolated knowledge questions, among other questions relating to screening and treatment preferences (Rimer *et al*, 2002; Wilt *et al*, 2001). For one of these studies (Rimer *et al*, 2002), this is likely to be because the main aim of the intervention was to promote uptake of breast screening, and for the second the main aim was to inform decision-making about screening, rather than to promote early presentation (Wilt *et al*, 2001).

Quality of studies

The quality of the five trials was moderate to good. All stated that they used randomisation although only one described how the randomisation sequence was generated (Wilt *et al*, 2001). The nature of the interventions meant that participants could not be kept blind to treatment allocation. None of the trials reported blinding of researchers to treatment allocation at the time of outcome data collection or analysis. All the studies examined baseline demographic differences between the trial arms and all examined change in knowledge or attitude score before and after the interventions except for one (Wilt *et al*, 2001), which examined outcomes only post-intervention. This may be important because there were baseline differences between the groups in this trial. All the reports reported withdrawals from the trial. The analysis was appropriate for most studies, except one cluster randomised controlled trial which did not analyse the data using the appropriate method for this design (Boundouki *et al*, 2004). The other cluster randomised controlled trial used appropriate random effects modelling (Glazebrook *et al*, 2006).

Findings

The trials were heterogeneous in terms of nature of intervention, populations, and outcomes measured and, therefore, we did not attempt any quantitative synthesis. All the five trials found that the intervention increased at least one aspect of cancer awareness, although the effects were fairly modest. The most intensive intervention –

tailored written information with a reinforcing newsletter at 12 months plus two telephone counselling sessions – increased the proportion who gave the correct answer to a question about age-related risk by 12% compared with usual care after two years (Rimer *et al*, 2002). Less intensive interventions increased cancer awareness more modestly (an interactive computer programme increased the average melanoma knowledge score by 6% after six months (Glazebrook *et al*, 2006) and a leaflet increased average oral cancer knowledge score by 4% after eight weeks (Boundouki *et al*, 2004)). A leaflet about prostate cancer increased the proportion who knew that the effectiveness of treatment in early prostate cancer is unknown by 12% after two weeks, but the magnitude of this difference may be at least partly due to the short follow-up (Wilt *et al*, 2001). This trial found that the leaflet did not increase knowledge of the natural history of untreated early prostate cancer.

We found some evidence that tailored print information was more effective than general information; tailored information increased average cancer knowledge scores by about 11% compared with no information and 4% compared with general information after three weeks (de Nooijer *et al*, 2004). Tailored print information modified attitudes towards paying attention to and seeking help for symptoms only very modestly (1-2% change in average scores) compared with no information (de Nooijer *et al*, 2004).

Community-level interventions examining cancer awareness

Description of studies and interventions

We found four studies examining the effectiveness of community-level interventions aiming to increase cancer awareness (Table 2): all were controlled studies but none used randomisation (Blumenthal *et al*, 2005; Kiekbusch *et al*, 2000; McCullagh *et al*, 2005; Skinner *et al*, 2000). The interventions were: a public education campaign to increase cancer awareness in African-American communities in two US cities (Blumenthal *et al*, 2005); an educational programme to promote breast cancer awareness in African-American women in one US city (Skinner *et al*, 2000); a multimedia programme to promote malignant melanoma knowledge sited in a kiosk in a public place in a Swedish village (Kiekbusch *et al*, 2000); and a health promotion initiative to promote testicular cancer knowledge and self-checking using posters, leaflets and shower gel in UK workplaces, health clubs and leisure centres (McCullagh *et al*, 2005).

The studies used different outcome measures, one encompassing knowledge, beliefs and attitudes (Blumenthal *et al*, 2005), the others only knowledge (Skinner *et al*, 2000; Kiekbusch *et al*, 2000; McCullagh *et al*, 2005); only one used a measure that was reported to have been validated (Skinner *et al*, 2000).

Quality of studies

In all the studies, the researchers selected controls appropriately by identifying communities or sites that were likely to have populations with similar characteristics to the intervention communities or sites, but were not likely to be contaminated by the

intervention. For two of the studies, (the Swedish study of the melanoma interactive multimedia programme (Kiekbusch *et al*, 2000), and the US study of the breast cancer educational programme (Skinner *et al*, 2000)), the researchers used only one control area. The public education campaign selected two control cities (Blumenthal *et al*, 2005) and the UK study of the testicular cancer initiative selected four control sites (McCullagh *et al*, 2005). While the study design in these four studies is stronger than if they were uncontrolled, differences between intervention and control areas can give rise to spurious findings of effectiveness or lack of effectiveness.

Findings

The studies examining the effectiveness of the public education campaign in the US and the effectiveness of the interactive multimedia kiosk in Sweden found no effect on knowledge (Blumenthal *et al*, 2005; Kiekbusch *et al*, 2000). The studies of the educational programme for breast cancer in the US and the UK health promotion initiative for testicular cancer found modest increases in knowledge, the first an increase in average breast cancer knowledge score of about 6% after eight months (Skinner *et al*, 2000) and the second an increase in average testicular cancer knowledge score of 20% after six weeks (McCullagh *et al*, 2005).

Community-level interventions examining early presentation outcomes

Description of studies and interventions

We found six studies; one interrupted time-series analysis (Catalano *et al*, 2003) and five before-and-after studies (Gabram *et al*, 2008; Geczi *et al*, 2001; Leander *et al*, 2007; MacKie *et al*, 2003; Rossi *et al*, 2000) (Table 3).

The interrupted time-series study examined the effectiveness of an annual media campaign, Breast Cancer Awareness Month, over 23 years in three US cities (Catalano *et al*, 2003). One before-and-after study examined the effectiveness of educational presentations at a range of sites aiming to downstage breast cancer at the time of diagnosis in African-American women in a US city (Gabram *et al*, 2008). The other four studies examined effectiveness of public education campaigns. Two aimed to promote early presentation in malignant melanoma: a poster and leaflet campaign in the West of Scotland (MacKie *et al*, 2003); and a media campaign followed by a leaflet to every household inviting every adult with risk factors for a skin check in one city in Italy (Rossi *et al*, 2000). One examined the effectiveness of a national testicular cancer awareness campaign in Hungary (Geczi *et al*, 2001) and another a national retinoblastoma awareness campaign in Honduras (Leander *et al*, 2007); both used broadcast and print media, and seminars and presentations to groups.

Three studies collected outcome data on time from symptom discovery to presentation or diagnosis (Geczi *et al*, 2001; Leander *et al*, 2007; MacKie *et al*, 2003). Five studies collected stage at diagnosis as an outcome (Catalano *et al*, 2003; Gabram *et al*, 2008; Leander *et al*, 2007; MacKie *et al*, 2003; Rossi *et al*, 2000).

Quality of studies

The time-series study was of high quality, the analysis controlling for autocorrelation, secular trends and events that might increase detection of all tumours (such as open enrolment to health insurance plans) by modelling as a function of the incidence of early stage colon cancers in men (Catalano *et al*, 2003). A before-and-after design is often the only feasible design for evaluating public education campaigns although this design is intrinsically limited because change in outcome cannot be attributed to the intervention alone. However, in four of the before-and-after studies, the outcomes were measured soon after the intervention (Gabram *et al*, 2008; Geczi *et al*, 2001; Leander *et al*, 2007; Rossi *et al*, 2000) so changes are fairly likely to be attributable to the intervention. The Scottish melanoma study examined outcomes ten years after the intervention (MacKie *et al*, 2003); however, a study examining earlier outcomes of the campaign suggest that the campaign immediately and significantly increased the proportion of malignant melanomas with Breslow thickness <1.5mm, and that this was sustained during the 1980s (MacKie and Hole, 1992).

Findings

The time-series study found that Breast Cancer Awareness Month, over 23 years led to the detection of 790 more early stage (in situ and local (confined to the breast)) breast cancers (an average of 34 per year) during the quarters in which the month occurred (Catalano *et al*, 2003). The authors did not report in situ and local cancer separately,

nor the proportion identified by screening. The study of educational presentations to downstage breast cancer in African-American women found that it reduced the proportion with advanced disease and increased the proportion with very early disease (Stage 0) (Gabram *et al*, 2008). The study of the Italian melanoma campaign found a reduction in mean tumour thickness over the period of the campaign compared with the four years before (Rossi *et al*, 2000) and the study of the Scottish melanoma campaign found an increase in the proportion of cases with tumour thickness <1.5mm (MacKie *et al*, 2003). This study also found an increase in the proportion delaying presentation for less than three months. The two other studies examining time from symptom discovery to diagnosis found that the campaigns had no effect (Geczi *et al*, 2001; Leander *et al*, 2007). However, the Honduran retinoblastoma campaign was associated with a reduction in the proportion presenting with advanced disease (Leander *et al*, 2007).

DISCUSSION

Summary of findings

We found limited evidence to inform policy on individual- or community-level interventions to promote cancer awareness. Randomised controlled trials of several individual-level interventions, which included written information (tailored and general), telephone counselling and a computer interactive programme, found modest positive effects on cancer knowledge or attitudes. Follow-up was for six months or less for all except one of the trials, so the long-term benefits are not clear. More intensive and tailored interventions are likely to be more effective. We found no evidence to inform policy on interventions delivered to individuals to promote early presentation. We found limited evidence of effectiveness of community-level interventions (small group educational programmes and health promotion programmes in workplaces, health clubs and leisure centres) to promote cancer awareness. We found good evidence that Breast Cancer Awareness Month in the US promotes diagnosis of breast cancer at an early stage and some evidence that educational interventions by community health advocates and public education campaigns downstage breast cancer, malignant melanoma and retinoblastoma and reduce time from symptom discovery to initial presentation in melanoma. Only for the Scottish malignant melanoma campaign did we find any evidence that the effect was sustained over a number of years.

Our systematic review has identified stronger evidence for interventions to promote cancer awareness and early presentation than the previous report, which found five studies (seven reports) that would have met our inclusion criteria had we extended our search to studies published earlier (MacDonald *et al*, 2004). Two of the reports examined earlier outcomes of the Scottish melanoma campaign that we have referred to above (Doherty and MacKie, 1988; MacKie and Hole, 1992). One study (a controlled study of a community-level intervention examining early presentation outcomes) examined the effectiveness of a cervical cancer group education intervention in rural India. The intervention increased the proportion of early cervical cancers diagnosed in the intervention area compared with neighbouring areas (Jayant *et al*, 1995). The remaining four reports examined three interventions aiming to increase malignant melanoma awareness: one individual-level intervention (an educational brochure distributed in the workplace to increase knowledge in Australian men aged 45 and older) examined in a randomised controlled trial, which found that it increased knowledge of melanoma compared with no brochure after three months (Hanrahan *et al*, 1995) and two fairly small scale UK public education campaigns, neither of which found good evidence of a reduction in tumour thickness after the campaigns, although this may have been due to small numbers of incident cancers (Whitehead *et al*, 1989; Graham-Brown *et al*, 1990; Healsmith *et al*, 1993).

Strengths and weaknesses of the review

Our study brings together the available evidence of effectiveness of interventions to promote cancer awareness and early presentation. Our search strategy was pragmatic and aimed to be specific but did not include the "grey" literature (that not published in peer-reviewed journals). There is some evidence that more comprehensive search strategies have little effect on the overall result of systematic reviews and may introduce bias by including studies with weaker designs (Egger *et al*, 2003). However, in systematic reviews of social interventions such as public education campaigns or health promotion initiatives, searching databases other than the standard biomedical ones may uncover important studies (Ogilvie *et al*, 2005). While we did not search other databases, we relaxed our study design inclusion criteria for evaluations of community-level interventions, recognising that controlled trials, and particularly randomised controlled trials, are more difficult to carry out.

Searching databases for studies of any kind of intervention to promote cancer awareness or early presentation is difficult because the search terms cannot focus on the intervention itself, unlike a search for studies of the effectiveness of a drug, or a particular type of complex intervention. A systematic review of interventions to communicate risk also documented this difficulty (Matthews *et al*, 1999). It is possible that we missed some studies because of the difficulties of designing a search with a high level of sensitivity and specificity.

Knowledge of screening, screening uptake and self-checking behaviour – for example, breast checking (including breast self-examination) or testicular checking – may be considered to be important elements of cancer awareness. We excluded studies of interventions examining only the outcomes of knowledge or uptake of breast or cervical screening because these have been covered by other studies (Bonfill Cosp *et al*, 2001; Forbes *et al*, 2001). We excluded studies examining outcomes of self-checking behaviour because the effectiveness of different modes of self-examination has not been established.

Strengths and weaknesses of the available evidence

For interventions delivered at an individual level, we found five fairly well-conducted randomised controlled trials examining awareness outcomes. None examined early presentation outcomes. In two of the trials, only one or two relevant knowledge questions were included as outcomes (Rimer *et al*, 2002; Wilt *et al*, 2001) because the main aim of the interventions were not, primarily, to increase cancer awareness to promote early presentation but to promote breast cancer screening in one (Rimer *et al*, 2002), and decision-making about prostate cancer screening in the other (Wilt *et al*, 2001). The other three interventions did aim mainly to increase awareness to promote early presentation, in malignant melanoma (Glazebrook *et al*, 2006) oral cancer (Boundouki *et al*, 2004), and a range of cancers (de Nooijer *et al*, 2004).

Cancer awareness was measured in a number of ways. Only one trial used a knowledge scale that was reported to have been validated (Boundouki *et al*, 2004). Because of this and the short follow-up in all except one trial, it is not possible to assess whether the increases in awareness would be sufficiently comprehensive, large or sustained to lead to significant behavioural change in the event of symptom discovery.

One of the difficulties of evaluating community-level interventions using the positivist methods conventional in medical research is that these methods are less widely accepted by social science and health promotion disciplines involved in designing them (Green and Tones, 1999; Ogilvie *et al*, 2005). Another is that the interventions are usually complex (multi-component) and dependent on context, and controlled trials, let alone randomised controlled trials, are often very difficult (Thomson *et al*, 2004). We found four controlled studies (not using randomisation) of community-level interventions to increase cancer awareness. Interpretation of findings is limited by the relatively weak study design. The studies used a range of outcome measures; only one used a measure that was reported to be validated (Skinner *et al*, 2000). Two studies found no significant effects on cancer awareness (Blumenthal *et al*, 2005) (Kiekbusch *et al*, 2000); whether this is due to intrinsic lack of effectiveness of the interventions, invalid outcome measures or to limitations of study design is unknown. Two found increases in cancer awareness: one eight months after an intensive educational programme

(Skinner *et al*, 2000) and one six weeks after a poster and leaflet initiative (McCullagh *et al*, 2005). It is likely that the outcomes were attributable to the interventions but we cannot be sure of this because of the limitations of study design.

Overall, community level interventions to promote early presentation provided some evidence of effectiveness for breast cancer, melanoma and retinoblastoma. Five studies suggested educational campaigns may lead to downstaging cancer (Catalano *et al*, 2003; Gabram *et al*, 2008; MacKie *et al*, 2003; Rossi *et al*, 2000; Leander *et al*, 2007); however, all were uncontrolled so the results cannot be reliably attributed to the intervention. On the other hand, outcomes were measured soon after the intervention so it is more likely that the improvement can be attributed to it. Another problem with interpreting the findings is that it is not possible to attribute the downstaging of cancer to the effect of the campaigns on the public only – all the interventions are likely to have raised health professional awareness as well; in fact, most were specifically designed to do so.

The finding that Breast Cancer Awareness Month (Catalano *et al*, 2003) increased diagnosis of early stage tumours may be at least partly due to increased mammography uptake during the month or soon after, rather than early presentation with symptoms, so we cannot tell which kind of behaviour was promoted by the intervention. This is also true of the finding that educational presentations increased the proportion with stage 0 breast cancer (Gabram *et al*, 2008). The benefit of detecting

more stage 0/*in situ* cancers in terms of breast cancer outcomes is unknown, as some of the women with these cancers may never have experienced clinical problems, and may have received unnecessary investigations.

Stage at presentation is likely to be related to duration of time between symptom discovery and initial presentation but is not necessarily a reliable proxy because stage will also be influenced by the grade of the cancer. Few studies examined duration of symptoms from discovery to initial presentation (MacKie *et al*, 2003) (Geczi *et al*, 2001; Leander *et al*, 2007); two found no effect (Geczi *et al*, 2001; Leander *et al*, 2007). It is possible that these two studies found no effect on duration of symptoms because the campaigns may have advanced both the average date of symptom discovery and the average date of presentation – which would lead to presentation at an earlier stage but would have no effect on duration of symptoms.

Implications

We found some evidence that interventions delivered at an individual level can promote cancer awareness over the short term, but no evidence that these promote early presentation with cancer symptoms. Future research evaluating individual-level interventions to promote cancer awareness should attempt to use study designs that generate high quality evidence, (in other words, randomised controlled trials), measure outcomes over a longer term (months/years) and attempt to measure behavioural and stage outcomes, as well as knowledge and attitudes. We also highlight the need for

standardised and validated measures of cancer awareness for different cancers, similar to the Cancer Research UK Cancer Awareness Measure supported by the National Awareness and Early Diagnosis Initiative (Stubbings *et al*, 2009 this supplement). There is also a need for standardised and validated measures of duration of symptoms.

We found limited evidence that intensive education campaigns may lead to greater cancer awareness and earlier presentation over the short term. However, what exactly a campaign needs to include to make it work, to make it work over the longer term and in different settings, and to make it work cost-effectively are not clear and warrant more research.

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Figure 1. Flow of studies

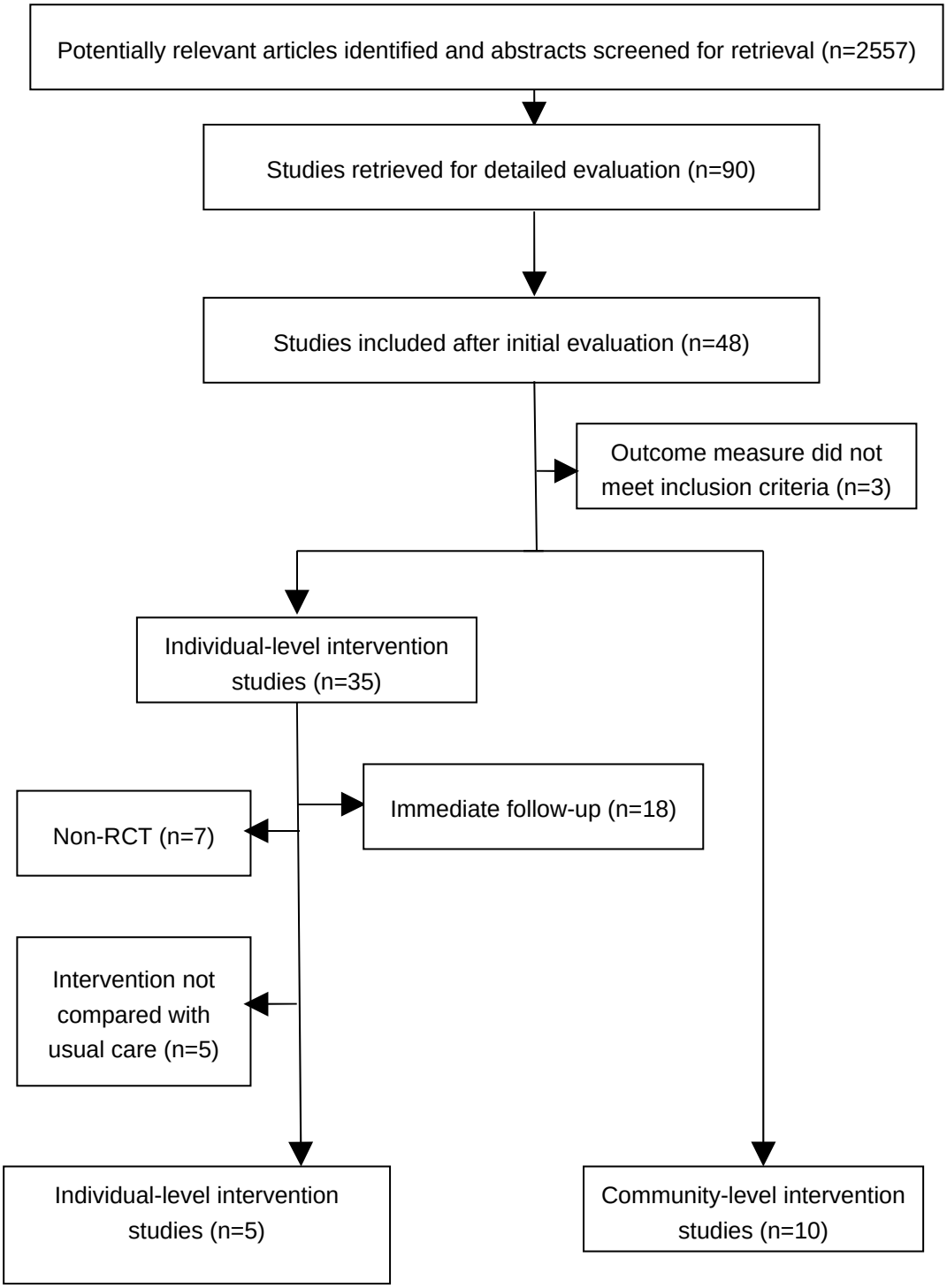

Table 1. Studies examining the effectiveness of individual-level interventions

Reference	Cancer	Intervention	Design	Participants	Outcome (time of measurement)	Results	Quality of evidence (see Appendix D)
(deNooijer *et al*, 2004)	Any cancer	Tailored information delivered by post: Letter tailored to individual based on knowledge and intentions. Included information on cancer symptoms (for several cancers), reasons for early detection, risk, breast and testicular self-examination, screening programmes. General information delivered by post: Brochure on early detection in several cancers used by Dutch Cancer Society.	RCT comparing: • Individually tailored information vs • General information vs • No information	1331 adults (mean age 47, 80% women) without cancer recruited through newspaper adverts in Netherlands	Knowledge of cancer symptoms (range 0, 15) (3 weeks) Attitude towards paying attention to symptoms (range -3, 3) (6 months) Attitude towards seeking help for symptoms (range -3, 3) (6 months)	Higher in tailored information group vs general information group vs control (9.85 vs 9.26 vs 8.21, p<0.001) Higher in tailored information group vs general information group vs control (2.05 vs 2.05 vs 1.96, p<0.01) Higher in tailored information group vs general information group vs control (2.13 vs 2.09 vs 1.99, p<0.001)	+
(Rimer *et al*, 2002)	Breast	Tailored information delivered by post: Booklet about breast cancer risk, risk factors and mammography tailored to individual based on responses provided during telephone call. Reinforcing newsletter 12 months later. Tailored information plus telephone counselling: As above plus 2 telephone calls (1 after booklet and 1 after newsletter) from trained health advisor asking questions about booklet/newsletter content to elicit questions and concerns.	RCT comparing: • Tailored print materials vs • Tailored print materials plus telephone counselling vs • Usual care	1091 women (aged 42-57) enrolled in health insurance plan in US	Knowledge that women aged >50 at higher risk of breast cancer than younger women (24 months)	Higher in tailored print materials plus telephone counselling group vs tailored print materials group vs usual care (32% vs 26% vs 20%, p=0.001)	+

Table 1. Studies examining the effectiveness of individual-level interventions

Reference	Cancer	Intervention	Design	Participants	Outcome (time of measurement)	Results	Quality of evidence (see Appendix D)
(Glazebrook *et al*, 2006)	Melanoma	Computer-based interactive educational programme to increase melanoma knowledge (including risk of sun exposure, how to protect skin, early signs) accessed through dedicated workstation in GP practice.	Cluster RCT (unit of randomisation = practice) comparing: • Educational programme vs • No programme	589 adults (mean age 38, 80% women) recruited from people with 1+ risk factor for melanoma attending general practice in UK	Knowledge of how to reduce risk of melanoma, risk factors, symptoms (range 0, 12) (6 months)	Higher in programme group vs no programme group (4.12 vs 3.36, p<0.001)	++
Reference	**Cancer**	**Intervention**	**Design**	**Participants**	**Outcome (Time of measurement)**	**Results**	**Quality of evidence** (see Appendix D
(Boundouki *et al*, 2004)	Oral	Leaflet to increase knowledge of oral cancer signs, risk factors and how to detect oral cancer, given out in waiting room.	Cluster RCT (unit of randomisation = session) comparing: • Leaflet vs • No leaflet	316 adults (mean age 47, 59% women) attending dentist in UK	Knowledge of oral cancer (range 0, 36) (8 weeks)	Higher in leaflet group vs no leaflet group (30.3 vs 29.0, p<0.001)	+
(Wilt *et al*, 2001)	Prostate	Leaflet to increase knowledge about risks and benefits of early prostate cancer detection and treatment delivered by post.	RCT comparing: • Leaflet vs • No leaflet	550 men (mean age 72) attending a primary care centre in US	Knowledge of natural history of untreated early prostate cancer (2 weeks) Knowledge that effectiveness of treatment in early prostate cancer is unknown (2 weeks)	No difference Higher in leaflet group vs no leaflet group (56% vs 44%, p=0.04)	+

Table 1. Studies examining the effectiveness of individual-level interventions

Reference	Cancer	Intervention	Design	Participants	Outcome (time of measurement)	Results	Quality of evidence (see Appendix D)

Table 2. Studies examining the effectiveness of community-level interventions on cancer awareness outcomes

Reference	Cancer	Intervention	Design	Population providing outcome data	Outcome	Results
(Blumenthal DS *et al*, 2005)	Any cancer	Public education campaign in 2 US cities (Nashville, Atlanta) to increase knowledge of several cancers in African-American communities, delivered by broadcast and print media, lectures, workshops, lectures, presentations over 18 months in 1994-6.	Controlled study (non-randomised) comparing: • Areas with black population in Nashville and Atlanta vs • Areas with black population in 2 cities receiving no campaign	African-American adults living in the 4 cities approached by random digit dialling (4053 before intervention; 3914 after intervention)	Knowledge, beliefs and attitudes towards cancer risk factors and screening	No difference. Quantitative data not provided.
(Skinner *et al*, 2000)	Breast	Educational programme delivered in small groups by a health professional to 32 women (mainly African-American) over three sessions, to increase breast cancer knowledge and screening uptake and promoting message dissemination to others in the social network.	Controlled study (non-randomised) in 1 US city (St Louis) comparing: • 1 managed social network for low income elderly people receiving the programme vs • 1 similar managed social network not receiving the programme	153 women (mean age 73) 99% African-American, members of the social network provided data both before and after intervention	Knowledge of breast cancer symptoms, risk factors and risk (range 0, 8) after 8 months	Higher in group education programme vs control networks 4.1 vs 3.6, $p<0.0001$)

Table 1. Studies examining the effectiveness of individual-level interventions

Reference	Cancer	Intervention	Design	Participants	Outcome (time of measurement)	Results	Quality of evidence (see Appendix D)
(Kiekbusch *et al*, 2000)	Melanoma	Interactive multimedia programme housed in kiosk in the centre of a village (in the pharmacy, then health centre, then library) to increase melanoma knowledge over 3 years.	Controlled study (non-randomised) in Sweden comparing: • 1 village receiving kiosk vs • 1 similar village not receiving kiosk	Swedish adults aged 20-59 living in the villages recruited from population registries (648 before intervention; 604 after intervention)	Knowledge of melanoma symptoms, risk factors, risk, preventive measures (range 1, 3) at the end of intervention	No difference (kiosk village vs control village: Men: 2.70 vs 2.68, p-value not provided; women: 2.72 vs 2.75, p-value not provided)	
(McCullagh *et al*, 2005)	Testicular	Health promotion initiative with printed shower gel sachets, stickers and posters displayed in changing rooms in workplaces, health clubs and leisure centres, to increase knowledge of testicular cancer and promote self-examination, delivered once to each site.	Controlled study (non-randomised) in the UK comparing: • 10 sites receiving the health promotion initiative vs • 4 sites receiving no health promotion initiative	Men aged 15-44 attending workplaces, health clubs and leisure centres in UK (518 before intervention; 356 after intervention)	Knowledge of testicular cancer symptoms, risk and survival (range 0, 5) after 6 weeks	Higher in health promotion initiative sites vs control sites (4 vs 3, p=0.014)	

Table 3. Studies examining the effectiveness of community-level interventions on early presentation outcomes

Reference	Cancer	Intervention	Design	Population providing outcome data	Outcome	Results
(Catalano *et al*, 2003)	Breast	22 annual public education broadcast and print media campaigns in 3 US cities (Atlanta, Detroit, San Francisco) about nature, detection and treatment of breast cancer (Breast Cancer Awareness Month) over 1975-97.	Interrupted time-series analysis	All cancer registrations in Atlanta, Detroit, San Francisco over 23 years	Additional in situ and local breast cancers	790 additional cancers over 23 years ($p<0.05$)

Table 1. Studies examining the effectiveness of individual-level interventions

Reference	Cancer	Intervention	Design	Participants	Outcome (time of measurement)	Results	Quality of evidence (see Appendix D)
(Gabram *et al*, 2008)	Breast	Educational presentations delivered to groups (mainly African-American) by community health advocates in churches, workplaces, schools etc, in 1 US city (Atlanta) to reduce breast cancer stage at presentation, during 2001-4.	Before-and-after study	Women diagnosed with breast cancer (89% African-American) in 1 Atlanta hospital in 2001 (n=113) and 2004 (n=128)	Proportion with stage 0 Proportion with stage IV	Increased (12% vs 26%, p<0.005) Reduced (17% vs 9%, p<0.05)	
(MacKie *et al*, 2003)	Melanoma	Public education campaign in West of Scotland to encourage early presentation in melanoma, delivered by posters and leaflets during 1986-8.	Before-and-after study	Scottish people diagnosed with melanoma in one Glasgow clinic in 1986 (n=125) and 2001 (n=162)	Proportion delaying presentation after symptom discovery 3 or fewer months Proportion with tumour thickness <1.5mm	Increased (16% vs 67%, 95% confidence interval for difference 42% to 61%) Increased (38% vs 72%, 95% confidence interval for difference 23% to 45%)	
(Rossi *et al*, 2000)	Melanoma	Public education campaign in Padova, Italy with broadcast and print media campaign followed by leaflet about symptoms and risk factors for melanoma and skin self-examination, inviting adults to request skin check, delivered by post to every family in Padova over 1991-6.	Before-and-after study	Padova residents diagnosed with melanoma between 1987-1990 (n=79) and 1991-1996 (n=137)	Mean tumour thickness	Reduced (2.0mm vs 1.5 mm, p<0.02)	
(Geczi *et al*, 2001)	Testicular	National Hungarian public education campaign about risk factors, importance of early detection and self-examination in testicular cancer, delivered by broadcast and print media and at events over 1995-8.	Before-and-after study	Hungarian men diagnosed with testicular cancer in 1994 (n=230) and 1998 (n=214)	Time from symptom discovery to diagnosis	No change	

Table 1. Studies examining the effectiveness of individual-level interventions

Reference	**Cancer**	**Intervention**	**Design**	**Participants**	**Outcome (time of measurement)**	**Results**	**Quality of evidence** (see Appendix D)
(Leander *et al*, 2007)	Retinoblastoma	National Honduran public education campaign to increase awareness of early signs of retinoblastoma and to encourage early presentation, delivered by flyers, posters, broadcast and print media and seminars during 2003-5.	Before-and-after study	Honduran children diagnosed with retinoblastoma in 1995-2003 (n=59) and 2003- 2005 (n=23)	Proportion presenting with advanced disease Time from symptom discovery to diagnosis	Reduced (73% vs 35%, p=0.002) No change	

Appendix A: Search Strategy

Search number	Search Terms	Results
1	(delay* or late or later or early or earlier or postpone* or wait* or deny or denial or promot*).mp (mp=ti,ot,ab,nm,hw,tc,id,sh,tn,dm,mf)	3 471 505
2	(helpseeking or diagnos* or present* or detect* or present* or attend* or consult* or seek or sought or refer or treatment or care).mp	12 653 832
3	(symptom* and (detect* or duration or onset*)).mp	233 071
4	(neoplasm* or cancer* or tumor or tumour or malignan*).mp	3 530 224
5	((1 and 2) or 3) and 4	397 046
6	Health education.kf,sh,kw,id or “patient education as Topic”/	132 915
7	6 and 4	11 986
8	7 or 5	406 275
9	Limit 8 to yr =”2000-2008”	217 118
10	Limit 9 to human *(limit not valid in PsychInfo; records were retained)*	195 231
11	(aware* or knowledge* or attitude* or recogni* or lay concept* or health belief* or expectation or information* or education*).mp	3 652 313
12	Randomized Controlled Trial/ or randomized controlled trial*.mp or randomised controlled trial.mp or controlled trial*.mp or intervention.mp or Intervention Studies/ or Research Design/ or comparative study.mp or program evaluation.mp or campaign.mp or educational program*.mp or (before and after).mp or controlled study.mp	5 908 672
13	10 and 11 and 12	11 017
14	Immunohistochemistry.mp or stroke.mp or exp nursing staff/ or exp medical errors/ or exp malpractice/ or exp liability, legal/ or exp disease models,animal/ or exp models, biological/ or models, animal/ or ((exp RNA, neoplasm/ or exp RNA, messenger/ or exp sequence analysis, RNA/ or exp RNA/ or exp signal transduction/ or transforming growth factor beta/ or exp DNA fragmentation/ or exp apoptosis/ or exp adenoviridae/ or exp genes/ or exp gene expression/ or exp cell communication/ pr exp antigens/ or exp alternative splicing/ or exp MicroRNAs/ or gene expression/ or exp membrane proteins/ or exp DNA-binding proteins/ or	16 595 285

	intracellular signalling peptides.mp) and proteins.mp) or exp protein isoforms/ or exp proto-oncogene proteins/ or exp sequence analysis/ or exp glycosolation/ or exp chemistry, pharmaceutical/ or exp drug carriers/ or exp drug resistance/ or exp antineoplastic agents/ or exp toxicity tests/ or exp radiation oncology/ or exp cell transformation, neoplastic/ or exp mammary neoplasms, experimental/ or exp tumor stem cells/ or exp pathology/ or exp therapeutics, ae, mo, cl, nu, ct, px, ec, st, es, sn, hi, td, is, ut, mt, ve or (pa or ge or ch or ai or ut or ec or mjo or dt or pp or et or og or ah or du or im or su of tu or re or th or ad or is).fs	
15	13 not 14	3 103
16	Remove duplicates from 15	2 759
17	Limit 16 to English language	2 561
	Further duplicates found and removed	2 557
	Included at abstract stage	90
	Included at full text stage	48

Appendix B: **Inclusion/exclusion criteria**

Individual level interventions: interventions delivered to identified individuals recruited to a study which attempted to collect outcome data from those individuals after the intervention.

Design:	RCT
Population:	Any, except if include only people at high genetic risk, health professionals only
Intervention:	Individual level intervention aimed at increasing cancer awareness or early presentation
Comparator:	Usual care, no intervention, placebo
Outcomes:	Knowledge or beliefs about: • cancer symptoms • risk of cancer • cancer risk factors • effectiveness of early treatment for cancer • natural history or prognosis of cancer • what to look for in detecting a change that might be cancer • attitude towards early detection behaviours and help-seeking • confidence to detect a change that might be cancer Time from symptom discovery to presentation or diagnosis; stage of disease at diagnosis; survival/mortality. We excluded studies examining exclusively any of the following outcomes: • knowledge of checking behaviour techniques (for example, how to check breasts, testicles or skin) • health-checking behaviour (for example, frequency of or competency in breast, testicular or skin self-examination) • knowledge of screening • knowledge of or beliefs about nature of treatment for cancer • intentions to take up screening

	• screening uptake We excluded studies with composite outcomes including the outcomes of interest, where these were not reported separately. We also excluded studies where the only post-intervention outcome measure was taken on the same day the intervention was delivered.

Community-level intervention: in which researchers did not control or identify which individual received the intervention

Design:	RCT Controlled study not using randomisation Before and after studies Time-series
Population:	Any, except if include only people at high genetic risk, health professionals only
Intervention:	Community-level intervention aimed at increasing cancer awareness or early presentation
Comparator:	Usual care, no intervention, placebo
Outcomes:	Knowledge or beliefs about: • cancer symptoms • risk of cancer • cancer risk factors • effectiveness of early treatment for cancer • natural history or prognosis of cancer • what to look for in detecting a change that might be cancer • attitude towards early detection behaviours and help-seeking • confidence to detect a change that might be cancer Time from symptom discovery to presentation or diagnosis; stage of disease at diagnosis; survival/mortality. We excluded studies examining exclusively any of the following outcomes: • knowledge of checking behaviour techniques (for example, how to check breasts, testicles or skin) • health-checking behaviour (for example, frequency of or competency in breast, testicular or skin self-examination) • knowledge of screening • knowledge of or beliefs about nature of treatment for cancer • intentions to take up screening • screening uptake

	We excluded studies with composite outcomes including the outcomes of interest, where these were not reported separately. We also excluded studies where the only post-intervention outcome measure was taken on the same day the intervention was delivered.

Appendix C: Data Extraction Form

1	**Study ID**	
1.1	ID number (reference manager ID)	
1.2	Reference	
1.3	1st reviewer	
1.4	Date of 1st review	
1.5	2nd reviewer	
1.6	Date of 2nd review	
2	**STUDY**	
2.1	Design	
2.2	Cancer site	
2.3	Method of participant selection	
2.4	Unit of randomisation	
2.5	Specific population	
2.6	Relevant data (i.e. the outcomes we are interested in - either cancer awareness or early presentation)	
2.7	Objectives of intervention and paper	
2.8	Summary of intervention, outcome measures and findings	
3	**PARTICIPANTS**	
3.1	Country	
3.2	N=	
3.3	Age	
3.4	Gender	
3.5	Ethnicity	

3.6	Marital status	
3.7	Education	
3.8	Experience of cancer	
3.9	Recruitment rate	
3.10.	Attrition rate	
3.11	Income	
3.12	Other demog. Info	
4	**METHODS**	
4.1	Duration of study	
4.2	Theoretical basis of intervention	
4.3	Type of intervention	
4.4	Follow-up duration (time between intervention and follow-up)	
4.5	Time points for evaluation?	
4.6	Who delivers the intervention?	
4.7	How is intervention delivered?	
4.8	How many times is the intervention delivered?	
4.9	Which outcomes have been measured?	
4.10.	How are outcomes assessed?	
4.11	If composite score, is it possible to extract relevant data?	
4.12	Validated measure (reference)	
4.13	Details of measure	
5	**STATISTICAL ANALYSIS**	
5.1	Statistical methods used	
6	**RESULTS**	
6.1	Knowledge of cancer symptoms	

6.2	Knowledge of risk factors	
6.3	Knowledge of cancer incidence	
6.4	Knowledge of screening availability and purpose	
6.5	Time from symptom discovery to presentation	
6.6	Time from symptom discovery to diagnosis	
6.7	Size of tumour at diagnosis	
6.8	Grade of tumour diagnosis	
6.9	Survival	
6.10.	Differences in outcomes by age/gender/ethnicity/income/education/other	
6.11	Other relevant observations and conclusions	

Appendix D: Checklist for methodological quality of randomised studies

1.1	The study addresses an appropriate and clearly focused question	Well covered Adequately addressed Poorly addressed	Not reported Not applicable
1.2	The assignment of subjects to treatment groups is randomised	Well covered Adequately addressed Poorly addressed	Not reported Not applicable
1.3	An adequate concealment method is used	Well covered Adequately addressed Poorly addressed	Not reported Not applicable
1.4	Subjects and investigators are kept ‘blind’ about treatment allocation	Well covered Adequately addressed Poorly addressed	Not reported Not applicable
1.5	The treatment and control groups are similar at the start of the trial	Well covered Adequately addressed Poorly addressed	Not reported Not applicable
1.6	The only difference between groups is the intervention under investigation	Well covered Adequately addressed Poorly addressed	Not reported Not applicable
1.7	All relevant outcomes are measured in a standard, valid and reliable way	Well covered Adequately addressed Poorly addressed	Not reported Not applicable

1.8	What percentage of the individuals or clusters recruited into each treatment arm of the study dropped out before the study was completed?		
1.9	All the subjects are analysed in the groups to which they were randomly allocated (often referred to as intention to treat analysis)	Well covered Adequately addressed Poorly addressed	Not reported Not applicable
1.10	Where the study is carried out at more than one site, results are comparable for all sites	Well covered Adequately addressed Poorly addressed	Not reported Not applicable
1.11	An appropriate analysis was used for cluster randomised controlled trials	Well covered Adequately addressed Poorly addressed	Not reported Not applicable

The methodological quality of the study is rated based on your responses to the appropriate methodology checklist using the following coding system:

++	**All or most** of the criteria have been fulfilled. Where they have not been fulfilled the conclusions of the study are thought very unlikely to alter.
+	**Some** of the criteria have been fulfilled. Those criteria that have not been fulfilled or not adequately described are thought unlikely to alter the conclusions.
-	**Few or no** criteria fulfilled. The conclusions of the study are thought likely or very likely to alter.

Notes:

1.1 Unless a clear and well defined question is specified, it will be difficult to assess how well the study has met its objectives or how relevant it is to the question you are trying to answer on the basis of its conclusions. Consider if the question is 'focused' in terms of the population studied, the intervention given and the outcomes chosen.

1.2 Random allocation of patients to receive one or other of the treatments under investigation, or to receive either treatment or placebo, is fundamental to this type of study. If the description of randomisation is poor, the study should be given a lower quality

rating. Consider the following points: whether the randomisation process was truly random, whether the method of allocation was described (stratification used to balance randomisation?), how the randomisation schedule was generated, how a participant was allocated to a study group and if there were any differences reported that might have explained any outcome(s) (confounding).

1.3 Allocation concealment refers to the process used to ensure that researchers are unaware which group patients are being allocated to at the time they enter the study. If the method of concealment used is regarded as poor, or relatively easy to subvert, the study should be given a lower quality rating.

1.4 Blinding refers to the process whereby people are kept unaware of which treatment an individual patient has been receiving when they are assessing the outcome for that patient. The higher the level of blinding, the lower the risk of bias in the study. Consider the following points: the fact that blinding is not always possible, whether every effort was made to achieve blinding and 'observer bias'.

1.5 Participants selected for inclusion in a trial must be as similar as possible. The study should report any significant differences in the composition of the study groups in relation to gender mix, age, stage of disease (if appropriate), social background, ethnic origin, or comorbid conditions. These factors may be covered by inclusion or exclusion criteria, rather than being reported directly. Failure to address this question, or the use of inappropriate groups, should lead to the study being downgraded.

1.6 If some patients received additional intervention, even if of a minor nature or consisting of advice and counselling rather than a physical intervention, this treatment is a potential confounding factor that may invalidate the results. If groups were not treated equally, the study should be rejected unless no other evidence is available (if used as evidence it should be treated with caution).

1.7 The primary outcome measures used should be clearly stated in the study. Where outcome measures require any degree of subjectivity, some evidence should be provided that the measures used are reliable and have been validated prior to their use in the study. Considered whether participant outcomes were reviewed at the same time intervals and if they received the same amount of attention from researchers and health workers (any differences may introduce performance bias).

1.8 The number of participants that drop out of a study should give concern if the number is very high. Conventionally, a 20% drop out rate is regarded as acceptable, but this may vary. Some regard should be paid to why participants dropped out, as well as how many. It should be noted that the drop out rate might be expected to be higher in studies conducted over a long period of time. A higher drop out rate will normally lead to downgrading, rather than rejection of a study.

1.9 It is rarely the case that all participants allocated to the intervention group receive the intervention throughout the trial, or that all those in the comparison group do not. However, participant outcomes must be analysed according to the group to which they were originally allocated irrespective of the intervention that they actually received (intention-to-treat analysis). The study may be rejected if it is clear that an intention-to-treat analysis was not used.

1.10 In multi-site studies, confidence in the results should be increased if it can be shown that similar results were obtained at the different participating centres.

1.11 The analysis chosen for cluster randomised controlled trials should be consistent with the design – it should take clustering into account. Valid approaches include: analysing clustered outcome data (unit of analysis is the same as that of randomisation) and individual level analysis accounting for clustering such as Random Effects Regression, Generalised Estimating Equations or Robust Standard Error.