

# Interventions for promoting participation in shared decision-making for children with cancer (Protocol)

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[Intervention Protocol]

# Interventions for promoting participation in shared decision-making for children with cancer

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## ABSTRACT

This is the protocol for a review and there is no abstract. The objectives are as follows:

To examine the effects of interventions to promote shared decision-making (SDM) for children with cancer who are aged four to 18 years.

## BACKGROUND

### Description of the condition

#### Participation in health matters

Children's rights to have their views heard in matters that affect their lives are now well established since the publication of the UN Convention treaty (United Nations 1989). There is considerable support for involving children in the healthcare decision-making process, and a dearth of well-articulated reasons to exclude them. Children's participation in health matters has been demonstrated to reduce healthcare use (McPherson 2006), increase adherence (De Winter 2002), increase internal locus of control and decision-making ability (Tiffenberg 2000), enhance competence, decrease fears and concerns (Runeson 2002), and promote satisfaction with health care (Freed 1998). Lack of involvement can have adverse consequences such as increased fears and anxieties, reduced self-esteem, depersonalization, and feeling unprepared for procedures (Coyne 2006). Therefore key documents emphasize the importance of children's participation in decision-making at a level commensurate with their experience, age, and abilities (Boylan 2004; Cavet 2005; Spinetta 2003).

#### Childhood cancers

This review focuses on shared decision-making (SDM) for children with cancer. There are 12 major types of childhood cancer but leukemias (blood cell cancers) and cancers of the brain and central nervous system account for more than half of the new cases diagnosed. The most common type of leukemia is acute lymphoblastic leukemia. The most common tumours are brain tumours (for example gliomas and medulloblastomas). The other solid tumours are less common (for example neuroblastomas, Wilms tumours, rhabdomyosarcoma and osteosarcoma). With significant medical advances in recent years, increasingly children are surviving cancer. The average 5-year survival rate for malignant cancers among children aged under 15 years is now approximately 79% in most countries (Gatta 2003).

#### Information sharing and decision-making

Cancer is a potentially life-threatening illness where important decisions are made at key points in the disease process. In many cases several treatment options exist with different possible outcomes and substantial uncertainty. It is important for children's psychological welfare that they are allowed a collaborative role in decision-making. Children with cancer generally prefer to be involved in decision-making (Stegenga 2008; Zwaanswijk 2007) and consider it important that they have the opportunity to take part in the decisions concerning their health care, even in end-of-life decisions (Hinds 2001). It appears that children with cancer

cope better with their illness when provided developmentally appropriate information at different stages of the illness trajectory (Ishibashi 2001; Last 1996). The International Society of Paediatric Oncology (SIOP) encourages doctors to share with children developmentally relevant information that will improve their ability to participate in the decision-making process (Spinetta 2003). Information sharing is a prerequisite to shared decision-making (Tates 2002a) but communication with children about their disease, treatment, and care provision is often poorly performed in practice (Scott 2003).

#### Participation in shared-decision making (SDM)

Parents and health professionals play an important role in communication interactions and can either facilitate or obstruct children's participation in decision-making. Although shared decision-making is increasingly valued, children's participation is often limited. Research in primary care settings has revealed a variety of ways in which doctors and parents frequently constrain children's participation in triadic interactions (Moore 2006; Tates 2002b). Research with adolescent cancer patients found that they struggle to assert their independence in decision-making and dislike being controlled by their parents (Dunsmore 1995). Participation in decision-making in childhood cancer is especially problematic because the management of the three-way relationship (parent, child, health professional) is complicated by issues of development and instincts for protection on the part of the adults involved (Dixon-Woods 2002; Young 2003).

There is currently no review of SDM interventions for children with cancer. There are, however, three related systematic reviews which contribute useful background information. Moore 2004 assessed whether communication skills training is effective in changing health professionals' behaviour in cancer care with regard to communication and interaction with patients. Based on three trials, they concluded that labour-intensive communication skills training can have a beneficial effect on behaviour change in professionals working with cancer patients. Ranmal 2009 updated the Scott 2003 review of the effectiveness of interventions for improving communication with children and adolescents about their cancer. They concluded from 10 studies that weak evidence exists to suggest that some children and adolescents may derive some benefit from specific information giving programmes and from interventions that aim to facilitate their reintegration in school and social activities. The interventions were directed towards communication generally rather than communication directed towards decision-making. O'Connor 2009 updated their 2003 review of decision aids for people facing health treatment or screening decisions. They concluded from 25 new studies that decision aids improve knowledge and realistic expectations, enhance active participation in decision-making, lower decisional conflict, decrease the proportion of people remaining undecided, and improve agreement between values and choices. Although this review showed

that decision aids can assist in promoting decision-making, none of the studies included interventions for children with cancer.

## Description of the intervention

Any intervention for SDM for children with cancer. The interventions should focus primarily on children, but can also include caregivers, parents, and health providers. The term parent refers to parent or the person or guardian serving in the parental role. For convenience, we will use the term parent in all circumstances.

## Defining shared decision-making (SDM)

Although significant conceptual work has taken place to define SDM many inconsistent definitions currently exist, which means that the concept is open to different interpretations (Makoul 2006). One conceptual framework has identified the core aspects of SDM (Charles 1997; Charles 1999). Drawing on this work, SDM is defined as having four necessary characteristics.

1. Shared decision-making involves at least two participants, the healthcare professional and child, and can involve three: healthcare professional, parent, and child.
2. Both the healthcare professional and child share information with each other.
3. Both the healthcare professional and child take steps to participate in the treatment decision-making process by expressing treatment preferences.
4. A treatment decision is made and both the healthcare professional and child agree to the decision.

## How the intervention might work

Interventions used to help children make shared decisions may consist of those aimed at improving information exchange, understanding, and communication; and those aimed at encouraging children to participate in decision-making. The interventions may aim to enhance children's abilities to participate in SDM or they might be interventions targeted at healthcare professionals or parents, or both, to encourage them to include children with cancer in the decision-making process. For example some interventions may help children to understand options and consequences whilst others may focus on developing children's skills. Other interventions may focus on educating parents and healthcare professionals and improving their motivation and skills to support children's participation.

## Why it is important to do this review

Despite increasing interest in children's participation in decision-making most of the research studies are essentially descriptive in nature, are mainly focused on proxy decision-making by parents

or health professionals, and do not provide information about what interventions promote children's participation in SDM. It is unclear what factors promote the SDM approach and what interventions are effective and suitable for children. No evidence-based guidelines exist to inform healthcare professionals on methods of supporting children's participation in SDM. Healthcare professionals and parents need to know how they should involve children in decision-making and what interventions are most effective in promoting SDM for children with cancer. Identifying such interventions will provide reassurance and guidance, and will potentially contribute to successful communication for children, parents, and the medical care team.

## OBJECTIVES

To examine the effects of interventions to promote shared decision-making (SDM) for children with cancer who are aged four to 18 years.

## METHODS

### Criteria for considering studies for this review

#### Types of studies

Randomised controlled trials (RCTs) of SDM interventions with children with cancer. We will exclude a cross-over trials as this design is not appropriate when an intervention can have a lasting effect that compromises entry to subsequent periods of the trial.

#### Types of participants

For the purpose of this review, a child is defined as a person between four and 18 years of age. Children younger than four years are excluded as they are potentially too young to adequately participate in the interventions.

A. Children diagnosed with any type or stage of cancer; studies with children diagnosed with cancer who also have other illnesses will be included.

B. We will include studies which involved parents or healthcare professionals, or both.

C. Studies may involve interventions given to only one group (e.g. children or parents or healthcare professionals), a combination of two groups (e.g. parents and children or healthcare professionals and children), or all three groups of participants (children, parents, and healthcare professionals). The term healthcare professionals refers to doctors and nurses and, for this review, excludes any other healthcare professional.

## Types of interventions

Studies will be included if they evaluate an intervention designed to promote SDM between children with cancer and parents and healthcare professionals. The types of decisions include decisions faced in the context of clinical care, such as treatment decisions, healthcare decisions, and research participation decisions. Studies focused on the involvement of children in consent or assent for involvement in clinical trials will be included. SDM interventions developed for research participation could be relevant for this review. At the same time, it must be noted that research participation decisions and treatment decisions differ in fundamental ways that may have substantial effects on information provision, competence to process the information, and the capacity to respond voluntarily to the options available. Decisions about research participation could result in different outcomes as compared to treatment decisions. Therefore, if sufficient studies are found on research participation decisions a subgroup analysis will be carried out to compare research decisions with clinical care decisions.

Interventions presented individually or in group sessions will be included. Examples of interventions could include the following.

- Providing information to a child, parent, or healthcare provider, or combinations of the three (communication interventions such as: booklet, video, web resources, workbook, posters, meetings, role play, puppets).
- Preparing the child or parent, or both, to participate in decision-making (educational interventions such as preparation for active participation, specific educational programs, question prompt sheet, decision aids or boards, leaflets, posters, media, implementation of models of participation, guidelines).
- Helping the child or parent, or both, to take part in the decision-making process (decision aids, online decision support tutorials, memory prompt, pre-consultation rehearsal questions).
- Training interventions targeted at healthcare professionals to promote implementation of SDM.
- Providing opportunities to review decisions made.

## Types of outcome measures

### Primary outcomes

The primary outcome is shared decision making (SDM) as measured with any validated scale. The process and outcome of SDM may be measured with scales such as: the Combined Outcome Measure for Risk Communication and Treatment Decision Making Effectiveness (COMRADE) scale (Edwards 2003), OPTION scale (Elwyn 2003), Decisional Conflict Scale (DCS) (O'Connor 1995) or with any other validated scale that measures involvement of patients in SDM. Numerous other potential measurement scales are listed in the systematic review of instruments that measure the involvement of patients in medical decision-making (Dy 2007). The diversity of instruments available for measuring

SDM demonstrates the broad range of constructs involved in its assessment (Dy 2007).

The primary outcome of SDM is often measured through direct observation of the behaviour exhibited by physician, parents, and patient.

- Patient and parents' behavioural outcomes (e.g. patterns of interaction with the medical care team, development of communication skills or techniques, level of involvement, question asking) may be measured with scales such as: the Child Behaviour Checklist (CBCL) (Achenbach 1991), Perceived Involvement in Care Scale (Lerman 1990), and the Autonomy Preference Index (Ende 1989).
- Health professionals' behavioural outcomes (e.g. patterns of communication, patient-directed questions, amount of deliberation, and time spent) may be measured by scales such as: the Roter Interaction Analysis System (RIAS) (Roter 1991) and the Decisional Conflict Scale (DCS) (O'Connor 1995).

The second primary outcome will be measures of the adverse effects:

- Anxiety (Spielberger 1973) or uncertainty (O'Connor 1995), or both.

### Secondary outcomes

If the primary outcome of interest is met then the secondary outcomes are:

- Measures of decisional quality (e.g. whether the patient or parent was adequately informed about the options, pros and cons discussed, preferences met, understanding checked, decisional conflict reduced). Scales will include the Satisfaction with Decision Scale (Holmes-Rovner 1996), Decisional Quality Inventory (DMQI) (Hollen 1999), and Decisional Conflict Scale (DCS) (O'Connor 1995).
- Measures of patient psychological outcomes (e.g. self-concept, sense of control, satisfaction, stress, anxiety). Scales such as the STAIC scale for children (Spielberger 1973), Satisfaction with Decision Scale (Holmes-Rovner 1996), or Multidimensional Health Locus of Control (MHLC) Scales (Wallston 1978) may be used.
- Measures of patient health outcomes (e.g. quality of life outcomes). Scales may be used such as: the Child Health Questionnaire (CHQ) (Landgraf 1996), Beck Depression Inventory (BDI) (Beck 1996), Pediatric Quality of Life Inventory (PedsQL 4.0) (Varni 2002), or study-specific observational rating scales.

### Search methods for identification of studies

See: Cochrane Childhood Cancer Group methods used in reviews (Module CCG).

We will search the following electronic databases: the Cochrane Central Register of Controlled Trials (CENTRAL) (*The Cochrane*

Library, latest issue), MEDLINE via PubMed (from 1945 to present), EMBASE Ovid (from 1980 to present), PsycINFO (from 1980 to present), CINAHL (from 1980 to present), and ERIC (from 1980 to present).

The search strategies for the different electronic databases (using a combination of controlled vocabulary and text words) are shown in the appendices ([Appendix 1](#), [Appendix 2](#), [Appendix 3](#), [Appendix 4](#), [Appendix 5](#), [Appendix 6](#)).

### Electronic searches

We will locate information about trials not registered in CENTRAL, MEDLINE, or EMBASE, either published or unpublished, by searching the reference lists of relevant articles and review articles. We will handsearch the conference proceedings of the International Society for Paediatric Oncology (SIOP) (from 2005 to 2009); International Conference on Shared Decision Making (from 2005 to 2009); Annual Scientific Meeting of the Society for Medical Decision Making (from 2005 to 2009); American Academy of Communication in Healthcare Annual Meeting (from 2005 to 2009); European Association of Communication in Health (from 2005 to 2009); the conference of the European Society of Medical Oncology (ESMO) (from 2005 to 2009); European Cancer Organisation (ECCO) (from 2005 to 2009); and International Scientific and Technical Proceedings database. We will also search Dissertation Abstracts (from 1980 to present) and Sociological Abstracts (from 1980 to present).

We will scan the ISRCTN (International Standard Randomized Controlled Trial Number) register and the National Institute of Health (NIH) Register for ongoing trials at: [www.controlled-trials.com](http://www.controlled-trials.com) and <http://clinicaltrials.gov>.

We will not impose language restrictions. We will update the searches every two years.

### Searching other resources

Authors of significant papers will be contacted to find other potentially relevant studies. Personal communication will be attempted with content experts in the field and with authors of trials and reviews to request information on any further trials they may be aware of, whether published, unpublished, or ongoing.

## Data collection and analysis

### Selection of studies

We will use the following process for selecting randomised controlled trials (RCTs) of SDM interventions for children with cancer.

1. Merge search results using reference management software (Endnote) and remove duplicate records of the same report.

2. Examine titles and abstracts to remove obviously irrelevant reports, being over-inclusive at this stage to ensure relevant reports are not accidentally removed.

3. The remaining abstracts (or an extract) will be examined by two review authors and independently screened for applicability according to the following criteria: randomised trial, intervention, children aged four to 18 years, parents, healthcare professionals, and outcomes.

4. A third person will be used to resolve any disagreements regarding selection of relevant studies and for full text articles.

5. Retrieve full text of the potentially relevant reports.

6. Link together multiple reports of the same study using the criteria detailed in section 7.2.2 of the Cochrane Handbook (Higgins 2008).

7. Examine full text reports for compliance of studies with eligibility criteria.

8. Correspond with investigators where appropriate to clarify study eligibility, and request missing data where necessary.

9. Make final decisions on study inclusion and proceed to data extraction.

### Data extraction and management

Two review authors will independently extract data for each included study on design, participants, interventions, population, and outcomes. For this, a data extraction form will be developed and piloted on a small number of studies. A third person will be used to resolve any discrepancies regarding data extraction. Data will be extracted on methods including design, recruitment, numbers, allocation, assessor, methods of analysis, intention to treat, follow up, and adverse effects. Participant details will be found including age, gender, ethnicity, inclusions, exclusions, diagnosis, stage of disease and treatment, setting, and country. Data will be unearthed about interventions including type, aims, content, mode of delivery, timing and frequency, duration; and also on outcomes including definition, timing, type of outcome, and instruments. When data are missing in a published report, the authors will be contacted for the missing information. As far as possible, information will also be collected from unpublished trials. The data from unpublished trials will be presented in an additional table.

### Assessment of risk of bias in included studies

The risk of bias will be independently assessed by two authors, one who is a content expert and one who has extensive knowledge of methodological aspects of systematic reviews. A third person will be used to resolve any discrepancies regarding methodological quality and sources of bias. If information is not clear, we will seek additional information from the principal investigator of the trial. We will assess the risk of bias for each trial in terms of selection bias (sequence generation and allocation concealment); performance bias (blinding of participants, blinding of personnel); detection

bias (blinding of outcome assessors); attrition bias (incomplete outcome data); and reporting bias (selective outcome reporting) as outlined in the module of the Cochrane Childhood Cancer Group (Kremer 2010). The risk of bias data will be presented in a 'Risk of bias' (ROB) table (as recommended in the guidelines of the 2008 Cochrane Handbook) (Higgins 2008). This table will be adjusted so all items described above can be included. In case a trial did not provide data on all outcomes included in the review, the authors will choose the option 'Unclear' for the outcomes that were not reported and leave the description field empty. This row of the table will not be included in the publication of the review. In addition to the ROB table, we will include a 'Methodological quality summary' in our review. If, in addition to the original paper, other sources of information have been used for the assessment of the risk of bias in a trial this will be clearly stated. If trials with a high and low risk of bias are simultaneously included in the analyses, a subgroup or sensitivity analysis will be performed to explore whether trial quality plays a role in determining the effect size.

### Measures of treatment effect

Data will be entered into RevMan using the duplicate data entry facility. If studies are sufficiently similar in design, interventions, and outcomes, we will undertake a meta-analysis. For dichotomous outcomes, relative risk (RR) and 95% confidence intervals (CI) will be calculated using a random-effects model. For continuous outcomes, weighted mean difference will be used if the outcomes are measured in a similar way across trials. The standardized mean difference (SMD) will be used to combine trials that measure the same outcome according to different methods.

### Unit of analysis issues

There may be trials where the unit of allocation is a cluster or the group. The groups may be, for example, wards or families. To avoid unit of analysis errors in cluster-randomised trials one can conduct the analysis at the same level as the allocation, using a summary measurement from each cluster. This may reduce the power of the study depending on the number and size of the clusters. Analysis can occur at the level of the individual while accounting for the cluster in the data. Statistical advice will be sought to determine the appropriate method (for example multilevel model, variance components analysis, or generalized estimating equations).

### Dealing with missing data

The principles of intention-to-treat (ITT) analyses are: 1) keep participants in the intervention groups to which they were randomised, regardless of the intervention they actually received; 2) measure outcome data on all participants; and 3) include all randomised participants in the analysis. If some participants were not analyzed in the group to which they were randomised, there may

be sufficient information in the trial report to restore them to the correct group. Alternatively, the trial authors may be able to provide the necessary information. If participants cannot be analyzed in their allocated groups, this will be clearly stated in the review (in the 'Characteristics of included studies' table and in the text). If initial participants were eventually lost to follow up or withdrew from the study and outcome data are not available, the primary analysis will use the number of participants with complete data as the denominator (that is in an 'available case' analysis).

### Assessment of heterogeneity

There could be considerable heterogeneity between included studies in terms of the specific interventions evaluated; the participants; the timing of the intervention and follow up; and the measurement instruments and statistical techniques. The  $I^2$  statistic will be used to measure heterogeneity as recommended in section 9.5.2 of Chapter 9 in the Cochrane Handbook for Systematic Reviews of Interventions (Higgins 2008). The  $\text{Chi}^2$  test for heterogeneity is unreliable as it has low power when the number of trials in the analysis is small and may give a non-significant result even when important heterogeneity is present. If  $I^2$  exceeds 50%, heterogeneity is substantial, which indicates that the trials differ by more than would be expected by chance. In other words, there is some other factor that partly determines what the result of a particular trial is. For example, the type of intervention could play a role; and if trials use different durations of intervention, their results may be different. It is, therefore, important to investigate the factors that may be responsible for heterogeneity. Sources will be investigated and where excessive heterogeneity is found the estimates will not be combined. A random-effects model will be used for all meta-analysis.

### Assessment of reporting biases

Reporting biases arise when the dissemination of research findings is influenced by the nature and direction of the results. The numerous types of reporting biases are outlined in Table 10.1a of Chapter 10 in the Cochrane Handbook (Higgins 2008). We will assess the reporting biases by conducting a comprehensive search for studies that meet the eligibility criteria, including grey literature and unpublished trials; using Endnote to remove duplicate studies; and contacting study authors for missing information. If a sufficient number of studies which explicitly use SDM are found, we will conduct a funnel plot and, if funnel plot asymmetry exists, then consider possible sources of asymmetry (as asymmetry may not indicate publication bias).

### Data synthesis

If studies are sufficiently similar in design, interventions, and outcomes, we will undertake a meta-analysis using a random-effects

model. If it is not possible to conduct a meta-analysis, we will perform a narrative synthesis. This is a structured summary and discussion of the studies' characteristics and findings. The narrative synthesis will be guided by considering four questions as outlined in section 9.1.2 Cochrane Handbook (Higgins 2008). These are:

1. what is the duration of the effect?
2. what is the size of the effect?
3. is the effect consistent across studies?
4. what is the strength of evidence for the effect?

### Subgroup analysis and investigation of heterogeneity

If a sufficient number of studies which explicitly use SDM are found, subgroup analysis will be carried out on patient characteristics and the interventions.

- Some interventions might have greater or lesser impact among different age groups. For example interventions for SDM may be more successful with older children as they may be more receptive to participation in SDM. If there are sufficient data, subgroup analysis will be carried out on studies with different age groups.
- Some interventions may have greater or lesser impact among different participant groups. If there are sufficient data, subgroup analysis will be carried out on studies with different groups. e.g. children, parents, and healthcare professionals.
- It is likely that many different types of interventions could be used. If there are sufficient data, subgroup analysis will be

conducted on the different types of interventions.

- For the reasons given above, interventions designed and used in research contexts may differ significantly from those designed and used in clinical care contexts. If there are sufficient data, subgroup analysis will be conducted on these two contexts.

### Sensitivity analysis

A sensitivity analysis is a repeat of the primary analysis, or meta-analysis, substituting alternative decisions or ranges of values for decisions that were arbitrary or unclear. The aim is to determine if the findings are robust to the decisions made in obtaining them. Sensitivity analysis will be performed by excluding those studies found to have a higher risk of bias.

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\* Indicates the major publication for the study

## APPENDICES

### Appendix I. Search strategy for PubMed

1. For **decision making** the following MeSH headings and text words will be used:

("attitude of health personnel"[Mesh Terms] OR "attitude to health"[Mesh Terms] OR "choice behavior"[Mesh Terms] OR "communication"[Mesh Terms] OR "consumer participation"[Mesh Terms] OR "cooperative behavior"[Mesh Terms] OR "decision making"[Mesh Terms] OR "decision support techniques"[Mesh Terms] OR "decision theory"[Mesh Terms] OR "educational technology"[Mesh Terms] OR "health education"[Mesh Terms] OR "informed consent"[Mesh Terms] OR "professional-family relations"[Mesh Terms] OR "psychology"[Subheading] OR affective aspect\* OR choice behavio\* OR clinical support technique\* OR cognitive aspect\* OR collaboration\* OR communication\* OR compliant behavio\* OR consensus OR consent\* OR consumer\* OR participation\* OR cooperative behavio\* OR co-operative behavio\* OR decision\* OR disput\* OR dissent\* OR doctor patient relation\* OR doctor-patient relation\*

OR educational technology OR emotional aspect\* OR health attitude\* OR health education OR health information OR health literacy OR illness behavior\* OR informed assent OR informed choice\* OR informed decision\* OR misinformation OR negotiati\* OR nursing role\* OR (nurse\* AND role\*) OR patient acceptance OR patient adherence OR patient attitude\* OR patient compliance OR patient cooperation OR patient co-operation OR patient education OR patient involvement OR patient non adherence OR patient non compliance OR patient nonadherence OR patient non-adherence OR patient noncompliance OR patient non-compliance OR patient participation OR patient preference\* OR patient satisfaction OR physician attitude OR physician patient relation\* OR physician-patient relation\* OR professional family disagreement\* OR professional family relation\* OR professional patient disagreement\* OR professional-family disagreement\* OR professional-family relation\* OR professional-patient disagreement\* OR psychosocial aspect\* OR psychosomatic aspect\* OR refusal participat\* OR shared decision\* OR sharing decision\* OR staff attitude\* OR treatment refusal\* OR uncertainty)

2. For **children 4-18 years** the following MeSH headings and text words will be used:

("child"[MeSH Terms] OR "schools"[MeSH Terms] OR "adolescent"[MeSH Terms] OR "minors"[MeSH Terms] OR "puberty"[MeSH Terms] OR "pediatrics"[MeSH Terms] OR "pediatric nursing"[MeSH Terms] OR "hospitals, pediatric"[MeSH Terms] OR adoles\* OR boy OR boys OR boyhood OR boyfriend OR child OR child's OR child's OR children\* OR girl\* OR highschool\* OR juvenil\* OR kid OR kids OR kindergar\* OR minors\* OR paediatric\* OR peadiatric\* OR pediatric\* OR prepuberty\* OR prepubescen\* OR preschool\* OR puber\* OR pubescen\* OR school\*[tiab] OR teen\* OR under ag\* OR underag\* OR youth\*)

3. For **cancer and childhood cancer** the following MeSH headings and text words will be used:

("Neoplasms"[Mesh Terms] OR "Oncology Service, Hospital"[Mesh Terms] OR AML OR B-cell\* OR cancer OR cancer's OR cancers\* OR cancerous OR carcinom\* OR Ewing\* OR gliom\* OR hematolo\* OR hematooncolog\* OR hemato-oncolog\* OR hepatoblastom\* OR hepatom\* OR hodgkin\* OR leukaemi\* OR leukemi\* OR lymphom\* OR malignan\* OR medulloblastom\* OR meningiom\* OR neoplasm\* OR nephroblastom\* OR neuroblastom\* OR non-hodgkin\* OR oncolog\* OR osteosarcom\* OR PNET\* OR retinoblastom\* OR rhabdomyosarcom\* OR sarcom\* OR T-cell\* OR teratom\* OR tumor OR tumor's OR tumors OR tumors' OR tumorous OR tumour\* OR wilms\*)

4. For **RCTs/CCTs** the following MeSH headings and text words will be used:

((random\* AND trial\*[tiab]) OR "randomized"[tiab] OR "randomly"[tiab] OR "Randomized Controlled Trial"[Publication Type] OR "Controlled Clinical Trial"[Publication Type] OR "Randomized Controlled Trials as Topic"[Mesh Terms] OR "Placebos"[Mesh Terms] or placebo\*)

The final combined search will be:

1 AND 2 AND 3 AND 4

[\* = 1 or more characters; tiab = title or abstract; sh = subheading]

## Appendix 2. Search strategy for EMBASE (Ovid)

1. For **decision making** the following Emtree terms and text words will be used:

1. attitude to health.mp. or exp attitude to health/
2. (Health Attitude or Health Attitudes).mp.
3. communication.mp. or exp interpersonal communication/
4. Personal Communication.mp.
5. Communications Personnel.mp.
6. (Communication Program or Communication Programs or collaboration).mp.
7. (misinformation or disput\$ or dissent\$).mp.
8. (cooperative behavior or cooperative behaviors or co-operative behavior or co-operative behaviors).mp. or exp cooperation/
9. exp patient compliance/ or Compliant Behavior.mp.
10. (Compliant Behaviors or Collaboration or Collaborations).mp.
11. (Health Knowledge and (attitude or attitudes)).mp.
12. exp human relation/ or (professional family disagreement\$ or professional patient disagreement\$ or professional-family disagreement\$ or professional-patient disagreement\$).mp.
13. (Professional-Family Relations or Professional Family Relations).mp.
14. (Professional-Family Relation or Professional Family Relation).mp.
15. (Professional Family Relationship or Professional Family Relationships).mp.
16. (doctor patient relation or physician patient relation).mp. or exp doctor patient relation/
17. (decision making or decision\$).mp. or exp decision making/

18. (choice behavior or choice behavior\$ or affective aspect\$ or cognitive aspect\$).mp.
19. (health education or health information or health literacy).mp. or exp health education/
20. (patient participation or participation\$).mp. or exp patient participation/
21. (consumer participation or consumer\$).mp. or exp consumer/
22. (patient attitude or emotional aspect\$).mp. or exp patient attitude/
23. physician attitude/ or physician attitude.mp.
24. illness behavior.mp. or exp illness behavior/
25. psychology.sh.
26. attitude of health personnel.mp. or exp health personnel attitude/
27. health knowledge.mp.
28. (patient acceptance or patient adherence or patient attitude\$ or patient compliance or patient cooperation or patient co-operation).mp.
29. (patient preference or patient involvement).mp.
30. (patient education or patient satisfaction or patient involvement or patient non adherence or patient non compliance or patient nonadherence or patient non-adherence or patient noncompliance or patient non-compliance).mp.
31. (decision aid or decision aids).mp.
32. exp decision support system/
33. (decision support system or decision support systems).mp.
34. (Decision Support Technique or Decision Support Techniques).mp.
35. (Decision Support Technic or Decision Support Technics).mp.
36. (Decision Support Model or Decision Support Models).mp.
37. (Decision Modeling or decision making or decision analysis or decision analyses).mp.
38. (clinical support technique or clinical support techniques).mp.
39. communication package.mp.
40. (shared decision or shared decision making).mp.
41. (shared decision or shared decisions).mp.
42. (sharing decision or sharing decisions).mp.
43. (informed choice or informed choices or informed decision\$).mp.
44. (informed consent or informed assent or consensus or consent).mp. or exp informed consent/
45. physician attitude.mp. or exp physician attitude/
46. patient decision making.mp. or exp patient decision making/
47. decision theory/ or decision theory.mp.
48. educational technology.mp. or exp educational technology/
49. (negotiati\$ or nursing role\$ or (nurs\$ and role\$)).mp.
50. (psychosocial aspect\$ or psychosomatic aspect\$ or refusal participat\$ or shared decision\$ or sharing decision\$ or staff attitude\$ or treatment refusal\$ or uncertainty).mp.
51. or/1-50

2. For **children 4-18 years** the following Emtree terms and text words will be used:

1. child/ or preschool child/ or school child/
2. adolescent/ or juvenile/ or boy/ or girl/ or puberty/ or prepuberty/ or pediatrics/
3. primary school/ or high school/ or kindergarten/ or nursery school/ or school/
4. (child\$ or children\$ or (school adj child\$) or schoolchild\$ or (school adj age\$) or schoolage\$ or (pre adj school\$) or preschool\$).mp.
5. (kid or kids or adoles\$ or teen\$ or boy or boys or boyhood or boyfriend or girl\$).mp.
6. (minors or minors\$ or (under adj ag\$) or underage\$ or juvenil\$ or youth\$).mp.
7. (puber\$ or pubescen\$ or prepubescen\$ or prepubert\$).mp.
8. (pediatric\$ or paediatric\$ or paediatric\$).mp.
9. (school or schools or (high adj school\$) or highschool\$ or (primary adj school\$) or (nursery adj school\$) or (elementary adj school) or (secondary adj school\$) or kindergar\$).mp.
10. exp pediatric nursing/ or pediatric nursing.mp.
11. exp pediatric hospital/ or (pediatric hospital or pediatric hospitals).mp.
12. or/1-11

3. For **cancer and childhood cancer** the following Emtree terms and text words will be used:

1. (leukemia or leukemi\$ or leukaemi\$ or (childhood adj ALL) or acute lymphocytic leukemia).mp.

2. (AML or lymphoma or lymphom\$ or hodgkin or hodgkin\$ or T-cell or B-cell or non-hodgkin).mp.
  3. (sarcoma or sarcom\$ or Ewing\$ or osteosarcoma or osteosarcom\$ or wilms tumor or wilms\$).mp.
  4. (nephroblastom\$ or neuroblastoma or neuroblastom\$ or rhabdomyosarcoma or rhabdomyosarcom\$ or teratoma or teratom\$ or hepatoma or hepatom\$ or hepatoblastoma or hepatoblastom\$).mp.
  5. (PNET or medulloblastoma or medulloblastom\$ or PNET\$ or neuroectodermal tumors or primitive neuroectodermal tumor\$ or retinoblastoma or retinoblastom\$ or meningioma or meningiom\$ or glioma or gliom\$).mp.
  6. (pediatric oncology or paediatric oncology).mp.
  7. ((childhood adj cancer) or (childhood adj tumor) or (childhood adj tumors) or childhood malignancy or (childhood adj malignancies) or childhood neoplasm\$).mp.
  8. ((pediatric adj malignancy) or (pediatric adj malignancies) or (paediatric adj malignancy) or (paediatric adj malignancies)).mp.
  9. ((brain adj tumor\$) or (brain adj tumour\$) or (brain adj neoplasms) or (brain adj cancer\$) or brain neoplasm\$).mp.
  10. (central nervous system tumor\$ or central nervous system neoplasm or central nervous system neoplasms or central nervous system tumour\$).mp.
  11. intracranial neoplasm\$.mp.
  12. LEUKEMIA/ or LYMPHOMA/ or brain tumor/ or central nervous system tumor/ or teratoma/ or sarcoma/ or osteosarcoma/
  13. nephroblastoma/ or neuroblastoma/ or rhabdomyosarcoma/ or hepatoblastoma/ or medulloblastoma/ or neuroectodermal tumor/ or retinoblastoma/ or meningioma/ or glioma/ or childhood cancer/
  14. or/1-13
4. For **RCTs/CCTs** the following Emtree terms and text words will be used:
1. Randomized Controlled Trial/
  2. Controlled Clinical Trial/
  3. randomized.ti,ab.
  4. placebo.ti,ab.
  5. randomly.ti,ab.
  6. trial.ti,ab.
  7. groups.ti,ab.
  8. (random\$ adj5 trial\$).mp.
  9. exp PLACEBO/ or (placebo or placebos).mp.
  10. or/1-9
- The final combined search will be:
- 1 AND 2 AND 3 AND 4
- [mp = title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer name; \$ = 1 or more characters; / = Emtree term; ti,ab = title or abstract; sh = subject heading]

### Appendix 3. Search strategy for Cochrane Central Register of Controlled Trials (CENTRAL)

1. For **decision making** the following text words will be used:

attitude of health personnel OR attitude to health OR choice behavior OR communication OR consumer participation OR cooperative behavior OR decision making OR decision support techniques OR decision theory OR educational technology OR health education OR informed consent OR professional-family relations OR psychology OR affective aspect\* OR choice behavio\* OR clinical support technique\* OR cognitive aspect\* OR collaboration\* OR communication\* OR compliant behavio\* OR consensus OR consent\* OR consumer\* OR participation\* OR cooperative behavio\* OR co-operative behavio\* OR decision\* OR disput\* OR dissent\* OR doctor patient relation\* OR doctor-patient relation\* OR educational technology OR emotional aspect\* OR health attitude\* OR health education OR health information OR health literacy OR illness behavio\*

OR

informed assent OR informed choice\* OR informed decision\* OR misinformation OR negotiati\* OR nursing role\* OR (nurse\* AND role\*) OR patient acceptance OR patient adherence OR patient attitude\* OR patient compliance OR patient cooperation OR patient co-operation OR patient education OR patient involvement OR patient non adherence OR patient non compliance OR patient nonadherence OR patient non-adherence OR patient noncompliance OR patient non-compliance OR patient participation OR patient preference\* OR patient satisfaction OR physician attitude OR physician patient relation\* OR physician-patient relation\* OR professional family disagreement\* OR professional family relation\* OR professional patient disagreement\* OR professional-family

disagreement\* OR professional-family relation\* OR professional-patient disagreement\* OR psychosocial aspect\* OR psychosomatic aspect\* OR refusal participat\* OR shared decision\* OR sharing decision\* OR staff attitude\* OR treatment refusal\* OR uncertainty

2. For **children 4-18 years** the following text words will be used:

(child OR schools OR adolescent OR minors OR puberty OR pediatrics OR pediatric nursing OR hospitals, pediatric OR adoles\* OR boy OR boys OR boyhood OR boyfriend OR child OR child's OR child's OR children\* OR girl\* OR highschool\* OR juvenil\* OR kid OR kids OR kindergar\* OR minors\* OR paediatric\* OR peadiatric\* OR pediatric\* OR prepuberty\* OR prepubescen\* OR preschool\* OR puber\* OR pubescen\* OR school\*[tiab] OR teen\* OR under ag\* OR underag\* OR youth\*)

3. For **cancer and childhood cancer** the following text words will be used:

(Neoplasms OR Oncology Service, Hospital OR AML OR B-cell\* OR cancer OR cancer's OR cancers\* OR cancerous OR carcinom\* OR Ewing\* OR gliom\* OR hematolo\* OR hematocolog\* OR hemato-oncolog\* OR hepatoblastom\* OR hepatom\* OR hodgkin\* OR leukaemi\* OR leukemi\* OR lymphom\* OR malignan\* OR medulloblastom\* OR meningiom\* OR neoplasm\* OR nephroblastom\* OR neuroblastom\* OR non-hodgkin\* OR oncolog\* OR osteosarcom\* OR PNET\* OR retinoblastom\* OR rhabdomyosarcom\* OR sarcom\* OR T-cell\* OR teratom\* OR tumor OR tumor's OR tumors OR tumors' OR tumorous OR tumour\* OR wilms\*)

The final combined search will be: 1 and 2 and 3

The search will be performed in title, abstract or keywords

[\* = 1 or more characters]

## Appendix 4. Search strategy for CINAHL

1. For **decision making** the following CINAHL subject headings and text words will be used:

(MH "Attitude of Health Personnel+" OR MH "Attitude to Health+" OR MH "Communication+" OR MH "Consumer Participation" OR MH "Cooperative Behavior" OR MH "Decision Making+" OR MH "Decision Support Techniques+" OR MH "Educational Technology" OR MH "Health Education+" OR MH "Consent+" OR MH "Professional-Family Relations" OR MH "Psychology+" OR MH "Nursing Role" OR affective aspect\* OR choice behavio\* OR clinical support technique\* OR cognitive aspect\* OR collaboration\* OR communication\* OR compliant behavio\* OR consensus OR consent\* OR consumer\* OR participation\* OR cooperative behavio\* OR co-operative behavio\* OR decision\* OR disput\* OR dissent\* OR doctor patient relation\* OR doctor-patient relation\* OR educational technology OR emotional aspect\* OR health attitude\* OR health education OR health information OR health literacy OR illness behavio\* OR informed assent OR informed choice\* OR informed decision\* OR misinformation OR negotiati\* OR nursing role\* OR (nurse\* AND role\*) OR patient acceptance OR patient adherence OR patient attitude\* OR patient compliance OR patient cooperation OR patient co-operation OR patient education OR patient involvement OR patient non adherence OR patient non compliance OR patient nonadherence OR patient non-adherence OR patient noncompliance OR patient non-compliance OR patient participation OR patient preference\* OR patient satisfaction OR physician attitude OR physician patient relation\* OR physician-patient relation\* OR professional family disagreement\* OR professional family relation\* OR professional patient disagreement\* OR professional-family disagreement\* OR professional-family relation\* OR professional-patient disagreement\* OR psychosocial aspect\* OR psychosomatic aspect\* OR refusal participat\* OR shared decision\* OR sharing decision\* OR staff attitude\* OR treatment refusal\* OR uncertainty)

2. For **children 4-18 years** the following CINAHL subject headings and text words will be used:

(MH "child+" OR MH "schools+" OR MH "adolescence+" OR MH "minors(legal)" OR MH "puberty+" OR MH "pediatrics+" OR MH "pediatric nursing+" OR MH "hospitals, pediatric" OR adoles\* OR boy OR boys OR boyhood OR boyfriend OR child OR child's OR child's OR children\* OR girl\* OR highschool\* OR juvenil\* OR kid OR kids OR kindergar\* OR minors\* OR paediatric\* OR peadiatric\* OR pediatric\* OR prepuberty\* OR prepubescen\* OR preschool\* OR puber\* OR pubescen\* OR TI school\* OR AB school\* OR teen\* OR under ag\* OR underag\* OR youth\*)

3. For **cancer and childhood cancer** the following CINAHL subject headings and text words will be used:

(MH "Neoplasms+" OR AML OR B-cell\* OR cancer OR cancer's OR cancers\* OR cancerous OR carcinom\* OR Ewing\* OR gliom\* OR hematolo\* OR hematocolog\* OR hemato-oncolog\* OR hepatoblastom\* OR hepatom\* OR hodgkin\* OR leukaemi\* OR leukemi\* OR lymphom\* OR malignan\* OR medulloblastom\* OR meningiom\* OR neoplasm\* OR nephroblastom\* OR neuroblastom\* OR non-hodgkin\* OR oncolog\* OR osteosarcom\* OR PNET\* OR retinoblastom\* OR rhabdomyosarcom\* OR sarcom\* OR T-cell\* OR teratom\* OR tumor OR tumor's OR tumors OR tumors' OR tumorous OR tumour\* OR wilms\*)

4. For **RCTs/CCTs** the following CINAHL subject headings and text words will be used:

((random\* AND trial\*) OR MH "Placebos" OR MH "Clinical Trials" OR (TI randomized OR AB randomized) OR (TI randomly OR AB randomly) OR placebo\*)

The final combined search will be: 1 AND 2 and 3 and 4

\* = zero of more characters, MH= CINAHL Heading, MH + = CINAHL Heading (Exploded), TI = Title, AB = abstract, \* = Truncation

## Appendix 5. Search strategy for ERIC

Search statement must be less than 500 characters

1. For **decision making** the following ERIC Thesaurus Descriptors subject headings and text words will be used:

(DECISION-MAKING#.DE. OR INTERPERSONAL-COMMUNICATION#.DE. OR HEALTH-EDUCATION#.DE.)

OR

(affective AND aspect\$) OR (choice AND (behaviour OR behaviours OR behavioural OR behavior OR behaviors OR behavioral)) OR (clinical AND support AND technique\$) OR (cognitive AND aspect\$) OR collaboration\$ OR (communication OR communications) OR (compliant AND (behaviour OR behaviours OR behavioural OR behavior OR behaviors OR behavioral)) OR consensus OR consent\$ OR consumer\$ OR participation\$ OR (cooperative AND (behaviour OR behaviours OR behavioural OR behavior OR behaviors OR behavioral))

OR

(co-operative AND (behaviour OR behaviours OR behavioural OR behavior OR behaviors OR behavioral)) OR decision\$ OR disput\$ OR dissent\$ OR (doctor AND patient AND (relation OR relations OR relationship OR relationships)) OR (doctor-patient AND (relation OR relations OR relationship OR relationships)) OR (educational AND technology) OR (emotional AND aspect\$) OR (health AND (atiitude OR attitudes)) OR (health AND education) OR (health AND information) OR (health AND literacy)

OR

(illness AND (behaviour OR behaviours OR behavioural OR behavior OR behaviors OR behavioral)) OR (informed AND assent) OR (informed AND choice\$) OR (informed AND decision\$) OR misinformation OR negotiati\$ OR (nurse\$ AND (role OR roles)) OR (patient\$ AND acceptance) OR (patient\$ AND adherence) OR (patient\$ AND (atiitude OR attitudes)) OR (patient\$ AND compliance) OR (patient\$ AND cooperation)

OR

(patient\$ AND co-operation) OR (patient\$ AND education) OR (patient\$ AND involvement) OR (patient\$ AND non AND adherence) OR (patient\$ AND non AND compliance) OR (patient\$ AND nonadherence)

OR

(patient\$ AND non-adherence) OR (patient\$ AND noncompliance) OR (patient\$ AND non-compliance) OR (patient\$ AND participation) OR (patient\$ AND preference\$) OR (patient\$ AND satisfaction) OR (physician\$ AND (atiitude OR attitudes)) OR (physician\$ AND patient\$ AND (relation OR relations OR relationship OR relationships))

OR

(physician-patient AND (relation OR relations OR relationship OR relationships)) OR (professional\$ AND family AND disagreement\$) OR (professional\$ AND family AND (relation OR relations OR relationship OR relationships)) OR (professional\$ AND patient AND disagreement\$)

OR

(professional-family AND disagreement\$) OR (professional-family AND (relation OR relations OR relationship OR relationships)) OR (professional-patient AND disagreement\$) OR (psychosocial AND aspect\$) OR (psychosomatic AND aspect\$)

OR

(refusal AND participat\$) OR (shared AND decision\$) OR (sharing AND decision\$) OR (staff AND (atiitude OR attitudes)) OR (treatment AND refusal\$) OR uncertainty

2. For **children 4-18 years** the following ERIC Thesaurus Descriptors subject headings and text words will be used:

(ADOLESCENTS#.W..DE. OR CHILDREN#.W..DE. OR SCHOOLS#.W..DE.) OR ((adolescent OR adolescents OR adolescence) OR (boy OR boys OR boyfriend OR boyhood) OR (child OR children) OR girl\$ OR highschool\$ OR juvenil\$ OR kid OR kids OR kindergar\$ OR minors\$ OR paediatric\$ OR peadiatric\$ OR pediatric\$ OR prepuberty\$ OR prepubescen\$ OR preschool\$ OR puber\$ OR pubescen\$ OR (school OR schools OR schooling OR schoolage OR schoolchild\$) OR teen\$ OR (under ADJ age) OR underage OR (youth OR youths))

3. For **cancer and childhood cancer** the following ERIC Thesaurus Descriptors subject headings and text words will be used:

CANCER#.W..DE. OR (AML OR B-cell\$ OR cancer OR cancer\$ OR carcinom\$ OR Ewing\$ OR gliom\$ OR hematolo\$ OR hematooncolog\$ OR hemato-oncolog\$ OR hepatoblastom\$ OR hepatom\$ OR hodgkin\$ OR leukaemi\$ OR leukemia\$ OR lymphom\$ OR malignan\$ OR medulloblastom\$ OR meningiom\$ OR neoplasm\$) OR (nephroblastom\$ OR neuroblastom\$ OR non-hodgkin\$ OR oncolog\$ OR osteosarcom\$ OR PNET\$ OR retinoblastom\$ OR rhabdomyosarcom\$ OR sarcom\$ OR T-cell\$ OR teratom\$ OR tumor\$ OR tumour\$ OR wilms\$)

4. For **RCTs/CCTs** the following text words will be used:

((random\$ AND trial\$) OR randomly OR randomized OR placebo\$)

The final combined search will be: 1 AND 2 AND 3 AND 4

#.DE. = ERIC Thesaurus Descriptor, #.W..DE. = ERIC Thesaurus Descriptor (Exploded), \$ = Truncation

## Appendix 6. Search strategy for PsycINFO

1. For **decision making** the following PsycINFO Thesaurus Descriptors subject headings and textwords will be used:

(DE "Decision Making" OR DE "Decision Support Systems" OR DE "Decision Theory" OR DE "Choice Behavior" OR DE "Group Decision Making" OR DE "Health Education" OR DE "Health Behavior" OR DE "Health Personnel Attitudes" OR DE "Health Attitudes" OR DE "Communication" OR DE "Interpersonal Communication" OR DE "Persuasive Communication" OR DE "Choice Behavior" OR DE "Informed Consent" OR affective aspect\* OR choice behavio\* OR clinical support technique\* OR cognitive aspect\* OR collaboration\* OR communication\* OR compliant behavio\* OR consensus OR consent\* OR consumer\* OR participation\* OR cooperative behavio\* OR co-operative behavio\* OR decision\* OR disput\* OR dissent\* OR doctor patient relation\* OR doctor-patient relation\* OR educational technology OR emotional aspect\* OR health attitude\* OR health education OR health information OR health literacy OR illness behavio\* OR informed assent OR informed choice\* OR informed decision\* OR misinformation OR negotiati\* OR nursing role\* OR (nurse\* AND role\*) OR patient acceptance OR patient adherence OR patient attitude\* OR patient compliance OR patient cooperation OR patient co-operation OR patient education OR patient involvement OR patient non adherence OR patient non compliance OR patient nonadherence OR patient non-adherence OR patient noncompliance OR patient non-compliance OR patient participation OR patient preference\* OR patient satisfaction OR physician attitude OR physician patient relation\* OR physician-patient relation\* OR professional family disagreement\* OR professional family relation\* OR professional patient disagreement\* OR professional-family disagreement\* OR professional-family relation\* OR professional-patient disagreement\* OR psychosocial aspect\* OR psychosomatic aspect\* OR refusal participat\* OR shared decision\* OR sharing decision\* OR staff attitude\* OR treatment refusal\* OR uncertainty)

2. For **Children 4-18 years** the following PsycINFO Thesaurus Descriptors subject headings and textwords will be used:

(DE "Schools" OR DE "Boarding Schools" OR DE "Charter Schools" OR DE "Colleges" OR DE "Elementary Schools" OR DE "Graduate Schools" OR DE "High Schools" OR DE "Institutional Schools" OR DE "Junior High Schools" OR DE "Kindergartens" OR DE "Middle Schools" OR DE "Military Schools" OR DE "Nongraded Schools" OR DE "Nursery Schools" OR DE "Seminaries" OR DE "Technical Schools" OR DE "Puberty" OR DE "Pediatrics" OR adoles\* OR boy OR boys OR boyhood OR boyfriend OR child OR child's OR child's OR children\* OR girl\* OR highschool\* OR juvenil\* OR kid OR kids OR kindergar\* OR minors\* OR paediatric\* OR peadiatric\* OR pediatric\* OR prepuberty\* OR prepubescen\* OR preschool\* OR puber\* OR pubescen\* OR TI "school\*" OR AB "school\*" OR teen\* OR under ag\* OR underag\* OR youth\*)

3. For **cancer and childhood cancer** the following PsycINFO Thesaurus Descriptors subject headings and textwords will be used:

(DE "Oncology" OR DE "Neoplasms" OR DE "Benign Neoplasms" OR DE "Breast Neoplasms" OR DE "Endocrine Neoplasms" OR DE "Leukemias" OR DE "Nervous System Neoplasms" OR DE "Terminal Cancer" OR AML OR B-cell\* OR cancer OR cancer's OR cancers\* OR cancerous OR carcinom\* OR Ewing\* OR gliom\* OR hematolo\* OR hematooncolog\* OR hemato-oncolog\* OR hepatoblastom\* OR hepatom\* OR hodgkin\* OR leukaemi\* OR leukemi\* OR lymphom\* OR malignan\* OR medulloblastom\* OR meningiom\* OR neoplasm\* OR nephroblastom\* OR neuroblastom\* OR non-hodgkin\* OR oncolog\* OR osteosarcom\* OR PNET\* OR retinoblastom\* OR rhabdomyosarcom\* OR sarcom\* OR T-cell\* OR teratom\* OR tumor OR tumor's OR tumors OR tumors' OR tumorous OR tumour\* OR wilms\*)

4. For **RCTs and CCTs** the following text words will be used:

(DE "Placebo" OR (random\* AND trial\*) OR randomly OR randomized OR placebo\*)

The final combined search will be: 1 AND 2 AND 3 AND 4

DE= PsycINFO Thesaurus Descriptors, TI = Title, AB = Abstract, \* = Truncation

## HISTORY

Protocol first published: Issue 2, 2011

## CONTRIBUTIONS OF AUTHORS

- Imelda Coyne is responsible for conceiving, designing, and coordinating the review
- Data collection for the review
  - Designing search strategies: I Coyne
  - Undertaking searches: I Coyne
  - Screening search results: I Coyne, L Shields, F Gibson
  - Selects relevant references of included studies and relevant reviews for inclusion: I Coyne, L Shields, F Gibson
  - Selects studies from conference proceedings for inclusion in review or for studies awaiting assessment table: I Coyne, F Gibson
  - Selects ongoing studies from trial databases for inclusion in ongoing studies table: I Coyne, F Gibson, D O'Mathuna
  - Organizing retrieval of papers: I Coyne
  - Prepare data extraction form: I Coyne, F Gibson
  - Screening retrieved papers against eligibility criteria: I Coyne, F Gibson, D O'Mathuna
  - Appraising quality of papers: I Coyne, F Gibson, D O'Mathuna, L Shields
  - Extracting data from papers: I Coyne, F Gibson
  - Writing to authors of papers for additional information: I Coyne
  - Providing additional data about papers: I Coyne
  - Obtaining and screening data on unpublished studies: I Coyne, F Gibson
- Data Management for the review
  - Entering data into Revman: I Coyne, F Gibson
  - Analysis of data: I Coyne, F Gibson, D O'Mathuna, L Shields
- Interpretation of data
  - Providing a methodological perspective: F Gibson, D O'Mathuna, L Shields
  - Providing a clinical perspective: F Gibson, L Shields
  - Providing a policy perspective- F Gibson, L Shields
  - Providing a consumer perspective: to be arranged
- Writing the protocol: I Coyne
- Writing the review: I Coyne, F Gibson, D O'Mathuna, L Shields
- Providing general advice on the review: F Gibson, D O'Mathuna, L Shields
- Securing funding for the review: I Coyne
- Performing previous work that was the foundation of the current review: I Coyne

## **DECLARATIONS OF INTEREST**

None

## **SOURCES OF SUPPORT**

### **Internal sources**

- No sources of support supplied

### **External sources**

- Ireland, Not specified.  
Health Research Board Cochrane Fellowship