Cochrane
Library

Cochrane Database of Systematic Reviews

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

Coyne I, O'Mathúna DP, Gibson F, Shields L, Leclercq E, Sheaf G

Coyne I, O'Mathúna DP, Gibson F, Shields L, Leclercq E, Sheaf G.
Interventions for promoting participation in shared decision-making for children with cancer.
Cochrane Database of Systematic Reviews 2016, Issue 11. Art. No.: CD008970.
DOI: [10.1002/14651858.CD008970.pub3](https://doi.org/10.1002/14651858.CD008970.pub3).

www.cochranelibrary.com

TABLE OF CONTENTS

ABSTRACT	1
PLAIN LANGUAGE SUMMARY	2
BACKGROUND	3
OBJECTIVES	4
METHODS	4
RESULTS	7
Figure 1.	8
DISCUSSION	9
AUTHORS' CONCLUSIONS	10
ACKNOWLEDGEMENTS	10
REFERENCES	11
CHARACTERISTICS OF STUDIES	14
APPENDICES	15
WHAT'S NEW	25
CONTRIBUTIONS OF AUTHORS	25
DECLARATIONS OF INTEREST	25
SOURCES OF SUPPORT	26
DIFFERENCES BETWEEN PROTOCOL AND REVIEW	26
INDEX TERMS	26

[Intervention Review]

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

Imelda Coyne¹, Dónal P O'Mathúna², Faith Gibson³, Linda Shields⁴, Edith Leclercq⁵, Greg Sheaf⁶

¹School of Nursing & Midwifery, Trinity College Dublin, Dublin, Ireland. ²School of Nursing and Human Sciences, Dublin City University, Dublin, Ireland. ³Department of Children's Nursing, London South Bank University, London, UK. ⁴School of Nursing, Midwifery and Indigenous Health, Charles Sturt University, Bathurst, Australia. ⁵Department of Paediatric Oncology, Emma Children's Hospital/Academic Medical Center, Amsterdam, Netherlands. ⁶The Library of Trinity College Dublin, Dublin, Ireland

Contact: Imelda Coyne, School of Nursing & Midwifery, Trinity College Dublin, 24 D'Olier St, Dublin, 2, Ireland. coynei@tcd.ie.

Editorial group: Cochrane Childhood Cancer Group.

Publication status and date: New search for studies and content updated (no change to conclusions), published in Issue 11, 2016.

Citation: Coyne I, O'Mathúna DP, Gibson F, Shields L, Leclercq E, Sheaf G. Interventions for promoting participation in shared decision-making for children with cancer. *Cochrane Database of Systematic Reviews* 2016, Issue 11. Art. No.: CD008970. DOI: [10.1002/14651858.CD008970.pub3](https://doi.org/10.1002/14651858.CD008970.pub3).

Copyright © 2016 The Cochrane Collaboration. Published by John Wiley & Sons, Ltd.

ABSTRACT

Background

This is an update of the Cochrane systematic review of shared decision-making (SDM) making published in 2013. 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 (1989). Children with cancer generally prefer to be involved in decision-making and consider it important that they have the opportunity to take part in decision-making concerning their health care, even in end-of-life decisions. There is considerable support for involving children in healthcare decision-making at a level commensurate with their experience, age and abilities. Thus, 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.

Objectives

To examine the effects of SDM interventions on the process of SDM for children with cancer who are aged four to 18 years.

Search methods

We searched the following sources for the review: Cochrane Central Register of Controlled Studies (CENTRAL) (the Cochrane Library 2016, Issue 1); PubMed (NLM) (1946 to February 2016); Embase (Ovid) (1974 to February 2016); CINAHL (EBSCO) (1982 to February 2016); ERIC (ProQuest) (1966 to February 2016); PsycINFO (EBSCO) (1806 to February 2016); BIOSIS (Thomson Reuters) (1980 to December 2009 - subscription ceased at that date); ProQuest Dissertations and Theses (1637 to February 2016); and Sociological Abstracts (ProQuest) (1952 to February 2016). In addition we searched the reference lists of relevant articles and review articles and the following conference proceedings (2005 up to and including 2015): American Academy on Communication in Healthcare (AACH), European Society for Medical Oncology (ESMO), European Cancer Organisation (ECCO), European Association for Communication in Healthcare (EACH), International Conference on Communication in Healthcare (ICCH), International Shared Decision Making Conference (ISDM), Annual Conference of the International Society for Paediatric Oncology (SIOP) and Annual Scientific Meeting of the Society for Medical Decision Making (SMDM). We scanned the ISRCTN (International Standard Randomised Controlled Trial Number) register and the National Institutes of Health (NIH) Register for ongoing trials on 29 February 2016.

Selection criteria

For this update, we included randomised controlled trials (RCTs) and controlled clinical trials (CCTs) of SDM interventions for children with cancer aged four to 18 years. The types of decisions included were: treatment, health care and research participation decisions. The primary outcome was SDM as measured with any validated scale.

Data collection and analysis

Two review authors undertook the searches, and three review authors independently assessed the studies obtained. We contacted study authors for additional information.

Main results

No studies met the inclusion criteria, and hence no analysis could be undertaken.

Authors' conclusions

No conclusions can be made on the effects of interventions to promote SDM for children with cancer aged four to 18 years. This review has highlighted the dearth of high-quality quantitative research on interventions to promote participation in SDM for children with cancer. There are many potential reasons for the lack of SDM intervention studies with children. Attitudes towards children's participation are slowly changing in society and such changes may take time to be translated or adopted in healthcare settings. The priority may be on developing interventions that promote children's participation in communication interactions since information-sharing is a prerequisite for SDM. Restricting this review to RCTs was a limitation and extending the review to non-randomised studies (NRS) may have produced more evidence. For this update, we included only RCTs and CCTs. Clearly more research is needed.

PLAIN LANGUAGE SUMMARY

Ways of helping children with cancer to take part in decisions about their health care

Review question

We reviewed the evidence about what helps children with cancer to take part in decisions about their health care. We found no studies.

Background

Cancer is a serious illness that involves complex treatments with unpleasant side effects. Children with cancer generally prefer to be involved in some way in decisions about their care and treatment. Involving children in decisions about their health care can help their understanding of the disease and treatment, reduce their fears, help them feel more prepared and to cope better with their cancer.

Study characteristics

The evidence is current to 29 February 2016. We did not find any studies that helped children to participate in decision-making with parents and healthcare staff.

Key results

At the moment, there is no evidence on ways of helping children with cancer take part in decisions about their health care. We need more high-quality research before definitive conclusions can be made.

Quality of the evidence

Not applicable as no eligible studies were found.

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 increase internal locus of control and decision-making ability (Tiffenberg 2000), promote preparedness (Coyne 2011a), decrease fears and concerns (Runeson 2002), increase adherence (De Winter 2002), reduce healthcare use (McPherson 2006), and promote satisfaction with health care (Alderson 2006). Lack of involvement can have adverse consequences such as increased fears and anxieties, reduced self-esteem, depersonalisation and feeling unprepared for procedures (Coyne 2006). Children who are not involved may assume their views are unimportant or irrelevant and may not seek to share their views in future (Coyne 2010). Therefore, key documents emphasise 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 focused on shared decision-making (SDM) for children with cancer. There are 12 major types of childhood cancer but leukaemias (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 leukaemia is acute lymphoblastic leukaemia. 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. Survival rates vary greatly according to the type of childhood cancer diagnosed. The mean five-year survival rate for all of the major childhood cancers among children aged under 15 years is now approximately 80% for children diagnosed in 1996 to 2004 (Jemal 2009).

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 with developmentally appropriate information at different stages of the illness trajectory (Ishibashi 2001; Last 1996). Current guidelines in paediatric oncology advocate that healthcare professionals encourage children to participate in medical decisions according to their developmental level and to share developmentally relevant information that will improve children's ability to participate in the

decision-making process (Spinetta 2003). Information sharing is a prerequisite to SDM (Tates 2001), but communication with children about their disease, treatment and care provision is often poorly performed in practice (Ranmal 2008).

Participation in shared decision-making

Health professionals and parents play an important role in communication interactions and can either facilitate or obstruct children's participation in decision-making (Wiering 2016). Although SDM is increasingly valued, children's participation in SDM may be limited because cancer is a life-threatening condition and treatment 'has to be' administered (Coyne 2014). It is further complicated by issues such as: adults' concerns about children's competence to participate, a desire to protect children from distressing information and the burden of decision-making, and the child's position in the three-way relationship (parent-child-healthcare professional) (Zwaanswijk 2007). 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 2002). Research with adolescents with cancer found that they struggle to assert their independence in decision-making and dislike loss of control (Coyne 2014; Wicks 2010).

Description of the intervention

Any intervention for SDM for children with cancer. The interventions should focus primarily on children, but can also include carers, parents and health providers. The term 'parent' refers to a 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

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.

- SDM involves at least two participants, the healthcare professional and child, and can involve three: healthcare professional, parent and child.
- Both the healthcare professional and child share information with each other.
- Both the healthcare professional and child take steps to participate in the treatment decision-making process by expressing treatment preferences.
- 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 while 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 provides reassurance and guidance, and potentially contributes to successful communication for children, parents and the medical care team.

This is an update of a previously published Cochrane review (Coyne 2013).

OBJECTIVES

To examine the effects of SDM interventions on the process of SDM for children with cancer who are aged four to 18 years.

METHODS

Criteria for considering studies for this review

Types of studies

We included randomised controlled trials (RCTs) and controlled clinical trials (CCTs) of SDM interventions with children with cancer. We excluded 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. CCTs using historical controls were not eligible for inclusion.

Types of participants

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

- Children diagnosed with any type or stage of cancer; studies with children diagnosed with cancer who also have other illnesses were eligible.
- Studies that involved parents or healthcare professionals, or both were eligible.
- Studies that involved interventions given to only one group (for example, children or parents or healthcare professionals), a combination of two groups (for example, parents and children or healthcare professionals and children), or all three groups of participants (children, parents and healthcare professionals) were eligible. The term 'healthcare professionals' refers to doctors and nurses and, for this review, excludes any other healthcare professional.

Types of interventions

Studies evaluating an intervention designed to promote SDM between children with cancer and parents and healthcare professionals were eligible for inclusion. The types of decisions included 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 were eligible for inclusion. SDM interventions developed for research participation were 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, a subgroup analysis was planned if the search found sufficient studies to compare research decisions with clinical care decisions, but since we identified no eligible studies, this was not feasible.

Interventions presented individually or in group sessions were eligible for inclusion. 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 specific educational programmes, memory prompts, pre-consultation rehearsal questions, question prompt sheets, decision aids or boards, online decision support tutorials, leaflets, posters, media, implementation of models of participation, guidelines);
- training interventions targeted at healthcare professionals to promote implementation of SDM;
- providing opportunities to review decisions made.

Types of outcome measures

Primary outcomes

- SDM as measured with any validated scale.
- Adverse effects (anxiety (Spielberger 1973) or uncertainty (O'Connor 1995), or both).

The processes and outcomes of SDM could have been measured with scales such as: the Combined Outcome Measure for Risk Communication and Treatment Decision Making Effectiveness (COMRADE) scale (Edwards 2003), Observing Patient Involvement (OPTION) scale (Elwyn 2003; Elwyn 2005), Decisional Conflict Scale (DCS) (O'Connor 1995), or with any other validated scale that measured involvement of people in SDM. Numerous other potential measurement scales are listed in the systematic review of instruments that measure the involvement of people 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's and parents' behavioural outcomes (for example, patterns of interaction with the medical care team, development of communication skills or techniques, level of involvement, question asking) could have been measured with scales such as: the Child Behavior Checklist (CBCL) (Achenbach 1991), Perceived Involvement in Care Scale (Lerman 1990), and the Autonomy Preference Index (Ende 1989).
- Health professionals' behavioural outcomes (for example, patterns of communication, patient-directed questions, amount of deliberation and time spent) could have been measured by scales such as: the Roter Interaction Analysis System (RIAS) (Roter 1991) and the DCS (O'Connor 1995).

Secondary outcomes

If the primary outcome of interest was met, then the secondary outcomes were:

- measures of decisional quality (for example, whether the child or parent was adequately informed about the options, pros and cons discussed, preferences met, understanding checked, decisional conflict reduced). Scales that could have been included were the Satisfaction with Decision Scale (Holmes-Rovner 1996), Decisional Quality Inventory (DMQI) (Hollen 1999), and DCS (O'Connor 1995);
- measures of patient psychological outcomes (for example, self-concept, sense of control, satisfaction, stress, anxiety). Scales such as the State-Trait Inventory for Children (STAIC) scale for children (Spielberger 1973), Satisfaction with Decision Scale (Holmes-Rovner 1996), or Multidimensional Health Locus of Control (MHLC) Scales (Wallston 1978) could have been used;
- Measures of patient health outcomes (for example quality of life outcomes). Scales could have been 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

We imposed no language restrictions.

Electronic searches

We searched the following sources: Cochrane Central Register of Controlled Studies (CENTRAL) (the Cochrane Library, 2016, Issue 1); MEDLINE (PubMed) (1946 to 29 February 2016); Embase (Ovid) (1974 to 29 February 2016); CINAHL (EBSCO) (1982 to 29 February 2016); ERIC (ProQuest) (1966 to 29 February 2016); PsycINFO (EBSCO) (1806 to 29 February 2016); BIOSIS (Thomson Reuters) (1980 to December 2009 - subscription ceased at that date); ProQuest Dissertations and Theses (1743 to 29 February 2016); and Sociological Abstracts (ProQuest) (1952 to 29 February 2016).

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; Appendix 7; Appendix 8; Appendix 9).

In the original version of this review we searched Dissertation Abstracts and the International Scientific and Technical proceedings database. However, Dissertation Abstracts is now part of ProQuest Dissertations and Theses, and the International

Scientific and Technical Proceedings database no longer exists, and could not be searched.

Searching other resources

We handsearched reference lists of relevant articles and the conference proceedings of the following (from 2005 up to and including 2015): American Academy on Communication in Healthcare (AACH), European Society for Medical Oncology (ESMO), European Cancer Organisation (ECCO), European Association for Communication in Healthcare (EACH), International Conference on Communication in Healthcare (ICCH), International Shared Decision Making Conference (ISDM), Annual Conference of the International Society for Paediatric Oncology (SIOP) and Annual Scientific Meeting of the Society for Medical Decision Making (SMDM). The terms used to search other resources are shown in the appendices (Appendix 10).

We scanned the ISRCTN (International Standard Randomised Controlled Trial Number) register and the National Institutes of Health (NIH) Register for ongoing trials (www.isrctn.com; clinicaltrials.gov) on 29 February 2016 (for search terms see Appendix 11).

Data collection and analysis

Selection of studies

We used the following process for selecting RCTs and CCTs of SDM interventions for children with cancer.

- We merged search results using reference management software (EndNote) and removed duplicate records of the same report.
- We examined titles and abstracts to remove obviously irrelevant reports, and were over-inclusive at this stage to ensure relevant reports were not accidentally removed.
- Two review authors examined the remaining abstracts (or an extract) and independently screened them for applicability according to the following criteria: RCT, CCT, intervention, children aged four to 18 years, parents, healthcare professionals and outcomes.
- A third review author resolved any disagreements regarding selection of relevant studies and for full-text articles.
- We retrieved full text of the potentially relevant reports.
- We linked multiple reports of the same study using the criteria detailed in Section 7.2.2 of the *Cochrane Handbook for Systematic Reviews of Interventions* (Higgins 2011).
- We examined full-text reports for compliance of studies with eligibility criteria.
- We corresponded with investigators where appropriate to clarify study eligibility and to request missing data where necessary.
- We constructed a flow chart.

Data extraction and management

Since we found no eligible studies for inclusion in this review, data analysis could not be performed. However, if eligible studies had been available, two review authors would have independently extracted data for each included study on design, participants, interventions, population and outcomes. For this, a data extraction form would have been developed and piloted on a small number of studies. A third review author would have resolved any

discrepancies regarding data extraction. Data would have been extracted on methods including design, recruitment, numbers, allocation, assessor, methods of analysis, intention to treat (ITT), follow-up and adverse effects. Participant details, including age, gender, ethnicity, inclusions, exclusions, diagnosis, stage of disease and treatment, setting and country, would have been identified. Data would have been collected about interventions including type, aims, content, mode of delivery, timing and frequency, and duration, and also on outcomes including definition, timing, type of outcome and instruments. If data were missing in a published report, the authors would have been contacted for the missing information. As far as possible, information would have been collected from unpublished trials. The data from unpublished trials would have been presented in an additional table.

Assessment of risk of bias in included studies

Two review authors (one content expert and one with extensive knowledge of methodological aspects of systematic reviews) would have independently assessed the risk of bias. A third review author would have resolved any discrepancies regarding sources of bias. We would have sought additional information from the principal investigator of the trial, if results were not clear. The risk of bias for each trial in terms of selection bias (sequence generation and allocation concealment); performance bias (blinding of participants and personnel); attrition bias (incomplete outcome data for each outcome separately); detection bias (blinding of outcome assessors for each outcome separately); reporting bias (selective outcome reporting) and other bias (other potential threats to validity if relevant for each outcome separately) as outlined in the module of Cochrane Childhood Cancer ([Kremer 2016](#)) would have been assessed, and presented in a 'Risk of bias' table (as recommended in the guidelines of the *Cochrane Handbook for Systematic Reviews of Interventions*) ([Higgins 2011](#)). Since we found no eligible studies for inclusion in this review, risk of bias assessment using the latest criteria of Cochrane Childhood Cancer ([Kremer 2016](#)) was not applicable. In addition to the 'Risk of bias' table, we would have included a 'Methodological quality summary' in our review. If, in addition to the original paper, other sources of information had been used for the assessment of the risk of bias in a trial this would have been clearly stated.

Measures of treatment effect

Data would have been entered into Review Manager 5 using the duplicate data entry facility ([RevMan 2014](#)). If studies were sufficiently similar in design, interventions and outcomes, we would have undertaken a meta-analysis. For dichotomous outcomes, risk ratio (RR) and 95% confidence intervals (CI) would have been calculated using a random-effects model. For continuous outcomes, mean difference would have been used if the outcomes were measured in a similar way across trials. The standardised mean difference (SMD) would have been used to combine trials that measured the same outcome according to different methods. Since we found no eligible studies for inclusion in this review, data analysis could not be performed.

Unit of analysis issues

There may be trials where the unit of allocation is a cluster or the group. For example, the groups may be 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 would have been sought to determine the appropriate method (for example multi-level model, variance components analysis, or generalised estimating equations). Since we found no eligible studies for inclusion in this review, data analysis could not be performed.

Dealing with missing data

The principles of ITT analyses are: keep participants in the intervention groups to which they were randomised, regardless of the intervention they actually received; measure outcome data on all participants; and include all randomised participants in the analysis. If some participants were not analysed in the group to which they were randomised, there may have been sufficient information in the trial report to restore them to the correct group. Alternatively, the trial authors may have been able to provide the necessary information. If participants could not be analysed in their allocated groups, this would have been clearly stated in the review (in the 'Characteristics of included studies' table and text). If initial participants were eventually lost to follow-up or withdrew from the study and outcome data were not available, the primary analysis would have used the number of participants with complete data as the denominator (that is, in an 'available case' analysis). Since we found no eligible studies for inclusion in this review, data analysis could not be performed.

Assessment of heterogeneity

There could be considerable heterogeneity between included studies in terms of the specific interventions evaluated, for example, participants, timing of the intervention and follow-up, and measurement instruments and statistical techniques. 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 used different durations of intervention, their results may have been different. The I^2 statistic would have been used to measure heterogeneity as recommended in Section 9.5.2 of the *Cochrane Handbook for Systematic Reviews of Interventions* ([Higgins 2011](#)). If the I^2 statistic exceeds 50%, heterogeneity is substantial, which indicates that the trials would differ by more than would have been expected by chance. It is important to investigate the factors that may be responsible for heterogeneity. Sources would have been investigated and where there was excessive heterogeneity the estimates would not have been combined. A random-effects model would have been used for all meta-analysis. Since we found no eligible studies for inclusion in this review, assessment of heterogeneity could not be performed.

Assessment of reporting biases

This is in addition to selective outcome reporting as outlined earlier in the [Assessment of risk of bias in included studies](#) section. 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 for Systematic Reviews of Interventions* ([Higgins 2011](#)). We assessed the reporting biases by conducting a comprehensive search for studies that met the eligibility criteria, including grey literature and unpublished trials; using Endnote to remove duplicate studies; and by contacting study authors for missing information. Funnel plots would only have been constructed when there was a sufficient number of

included studies (that is, at least 10 studies included in a meta-analysis) because otherwise the power of the tests would be too low to distinguish chance from real asymmetry (Higgins 2011). If a sufficient number of studies were found, we would have constructed a funnel plot and, if funnel plot asymmetry existed, then we would have considered possible sources of asymmetry (as asymmetry may not indicate publication bias). Since we found no eligible studies for inclusion in this review, assessment of reporting biases could not be performed.

Data synthesis

If studies were sufficiently similar in design, interventions and outcomes, we would have undertaken a meta-analysis using a random-effects model, or if this is not possible, using a narrative synthesis. The narrative synthesis would have been guided by considering four questions as outlined in Section 9.1.2 of the *Cochrane Handbook for Systematic Reviews of Interventions* (Higgins 2011). These are:

- What is the duration of effect?
- What is the size of effect?
- Is the effect consistent across studies?
- What is the strength of evidence for the effect?

The included studies would have been assessed for above issues. Since we found no eligible studies for inclusion in this review, data analysis could not be performed.

Subgroup analysis and investigation of heterogeneity

If a sufficient number of studies which explicitly used SDM were found, subgroup analysis would have been carried out on participant characteristics and 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 were sufficient data, subgroup analysis would have been carried out on studies with different age groups. Some interventions may have greater or lesser impact among different participant groups. If there was sufficient data, subgroup analysis would have been carried out on studies with different groups (for example, children, parents and healthcare professionals). It is likely that many different types of interventions could have been used. If there were sufficient data, subgroup analysis would have been 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. Since we found no eligible studies for inclusion in this review, subgroup analysis could not be performed.

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 would have been performed by excluding those studies with a higher risk of bias and also studies with an unclear risk of bias. Sensitivity analysis can only be performed if at least two studies remain in the analysis after exclusion of the studies with a high or unclear risk of bias. Since we found no eligible studies for inclusion in this review, sensitivity analysis could not be performed.

RESULTS

Description of studies

Results of the search

In the original version of this systematic review, the review authors identified 5364 potentially relevant documents from only the electronic databases, of which 5359 were excluded by reviewing titles and abstracts. Of the remainder, we retrieved four full publications for more detailed screening (Beale 2007; Dragone 2002; Jones 2010; Kato 2008). Following full scrutiny these four full-text articles, none of these studies measured the primary outcome of SDM, and hence no eligible studies for inclusion in this review were identified. The electronic search of the databases (Embase) yielded one abstract that was presented at the World Congress of Psychology conference in October 2011. The author was contacted and kindly sent us a copy of the abstract that was published (Kurt 2011). The author confirmed that the study was part of a doctorate thesis that has not been published yet. The author confirmed that the study did not measure the primary outcome of SDM. The electronic database search found three reviews that we had copies of already (Joosten 2008; Ranmal 2008; Scott 2003). Screening the reference lists of these reviews identified no eligible studies. The other searches did not yield any eligible studies for inclusion in this review.

For this update, the review authors identified an additional 2676 potentially relevant documents from the full search. After removing 614 duplicates, we excluded 2675 records after reviewing titles and abstracts. We retrieved one full-text publication for more detailed screening (Hollen 2013), which we excluded (see [Characteristics of excluded studies](#) table) (Figure 1).

Figure 1. Study flow diagram.

Included studies

The search identified no eligible studies for inclusion in this review.

Excluded studies

For the original version of the review, two of the excluded papers were from the same study, which was a multi-site RCT of a psychoeducational intervention with adolescents and young adults with cancer (aged 13 to 29 years) (Beale 2007; Kato 2008). The psychoeducational intervention was a video game called 'Re-Mission', which was compared with a regular commercial game. One paper reported on the effect of the video game (Re-Mission) on cancer-related knowledge (Beale 2007). The other paper from the same study reported on treatment adherence (primary outcome) and cancer-related knowledge; cancer-specific self-efficacy; and quality of life, stress and control (secondary outcomes). We excluded these studies because they did not include SDM as an outcome.

The excluded abstract by Kurt 2011 reported an RCT of Re-Mission compared with a regular commercial game in adolescents and young adults with cancer (aged 13 to 18 years). The purpose was to determine the effectiveness of a video game intervention for improving emotional and behavioural outcomes. We excluded this study because they did not include SDM as an outcome.

Two studies evaluated computer-based information programmes. One compared an interactive CD-ROM product (Kidz with Leukaemia: a Space Adventure) with a book by Lynn Baker for children aged four to 11 years with leukaemia and their parents (Dragone 2002). The outcomes measured were the children's health locus of control, understanding of leukaemia and satisfaction with the intervention. The other study compared a CD-ROM designed to teach 12- to 18-year-old people with solid tumours about their disease, treatment, coping skills and late effects (health problems that occur months or years after treatment has ended) with a

handbook (Jones 2010). We excluded these studies because they did not include SDM as an outcome.

For the update, we found one RCT which tested a decision aid for cancer-surviving adolescents related to engaging in substance abuse behaviours and measured decision-making as an outcome using a decision-making quality scale (Hollen 2013). We excluded this study because the children did not have cancer but were cancer survivors. The focus of this review is on children who currently have cancer and how SDM impacts on decisions related to their cancer care or even end-of-life care.

See also the [Characteristics of excluded studies](#) table.

Risk of bias in included studies

Since we found no eligible studies for inclusion in this review, risk of bias assessment using the latest criteria of the [Childhood Cancer Group](#) was not applicable.

Effects of interventions

Since we found no eligible studies for inclusion in this review, it was not possible to examine the effects of interventions to promote SDM for children with cancer aged four to 18 years.

DISCUSSION

Unfortunately, in both the original version of this review and this update we found no eligible studies for inclusion. Of the six studies that came closest to meeting the inclusion criteria of this review, five reported outcomes that could impact on the process of SDM through a variety of mechanisms (Beale 2007; Dragone 2002; Jones 2010; Kato 2008; Kurt 2011). In the five studies, the outcomes were: understanding, cancer-related knowledge, self-efficacy, stress and internal locus of control. The sixth study did not include children during their cancer treatment, but focused on decision-making for childhood cancer survivors (Hollen 2013). Improving understanding through information exchange and communication may encourage children to participate in decision-making. Reduction in stress may help children to absorb information more easily thus enabling them to become more involved in discussions about decisions (McCabe 1996). It is hypothesised that educational interventions that help support or enhance children's internal locus of control or health locus of control may encourage children to participate in decision-making. Perceived control over one's health can influence feelings of self-efficacy (Bandura 1977). Self-efficacy can both affect and be affected by information and communication (Makoul 1998). Therefore, interventions that enhance children's feelings of self-efficacy may help children to feel more confident to seek information and become involved in decision-making. Likewise, involvement in decisions may enhance self-efficacy (Miller 2012; White 1996).

Information exchange is commonly seen as a pre-requisite for participation in decision-making (Makoul 2006). Therefore, improvements to routine communications between child-parent-healthcare professional coupled with communication interventions may help children with cancer to participate in SDM in several ways. It may help children to understand their disease and treatment better so that with more knowledge they are enabled to offer their views (Coyne 2016; Hokkanen 2004). Improvement in communication interactions may help children to

become more familiar with healthcare professionals and to develop relationships with them. Feeling comfortable interacting with healthcare professionals may encourage children to seek inclusion in the decision-making process, to ask more questions and express their preferences (Zwaanswijk 2007). Ranmal 2008 reviewed the effectiveness of interventions for improving communication with children and adolescents about their cancer and concluded that there was weak evidence to suggest that some children and adolescents may derive some benefit from specific information-giving programmes. Interventions are needed both to improve communication and participation in decision-making.

With regard to changing professionals' behaviour, there are three related systematic reviews that contribute useful information. Moore 2013 assessed whether communication skills training was effective in changing health professionals' behaviour in cancer care with regard to communication and interaction with patients. They concluded that communication skills training can have a beneficial effect on behaviour change in relation to information-gathering and showing empathy. Légaré 2010 and concluded that the evidence was sparse and weak. They suggested that educational meetings, giving healthcare professionals' feedback or learning materials (or both), and using patient decision aids are some interventions that might be helpful. In an update of this review, Légaré 2014 reviewed interventions for increasing healthcare professionals' adoption of SDM but could not draw firm conclusions due to the low quality of evidence. They suggested that any interventions that actively target patients, healthcare professionals or both, are better than none. Thus, it is likely that interventions to improve the adoption of SDM by healthcare professionals working with children would need to target each member of the triad (parent-child-healthcare professional). Stacey 2014 reviewed decision aids for people facing health treatment or screening decisions and found that decision aids compared to usual care improve knowledge of options, reduce decisional conflict, have a positive effect on patient-practitioner communication and stimulate people to participate more in decision-making. They included studies involving people who were making decisions about screening or treatment options for themselves, for a child or for an incapacitated significant other. None of the studies included interventions for parents of children with cancer or for children with cancer. But this review is relevant as it showed that decision-aids stimulate adults and parents to participate more in the decision-making process.

Therefore, good-quality decision aids developed and tailored for children with cancer could be useful interventions to support children's efforts to participate in SDM. Decision aids that are developed in childhood cancer need to adhere to the International Patient Decision Aid Standards (IPDAS) Collaboration quality criteria on choice and the decision process (Elwyn 2006; O'Connor 2005). Professionals need to assess children's preferences for how they want to be involved in the decision-making process. The control preferences scale (Degner 1992) could be adapted and used to assess how children prefer to be involved in SDM. Joosten 2008 suggests that SDM can be an effective and useful way of reaching a treatment decision when people have to make long-term decisions as there are more chances to deliberate over decisions or to revisit decisions. Childhood cancer is a childhood illness with a complex and lengthy treatment trajectory, therefore SDM should be supported. In conclusion, more high-quality research is needed in order to answer the questions of the review.

SDM is a process in which children, parents and healthcare professionals share information, express treatment preferences and agree to the decision made. Children with cancer generally prefer to be involved in SDM and consider it important that they have the opportunity to take part in healthcare decision-making (Stegenga 2008; Zwaanswijk 2011), and sometimes in end-of-life decisions (Hinds 2005). Children should be involved as much as possible in decisions about their care, even when they are unable to make decisions on their own (Wood 2010). They often prefer a collaborative role in that they want to be involved but not necessarily to have full responsibility for the decision made (Coyne 2011a). Sometimes they may prefer a passive role in SDM because they are too ill or distressed by the treatments. They may prefer to hear information from their parents especially if it is 'bad' news or about adverse effects of treatment (Coyne 2010). Decision-making in childhood cancer can be challenging (Whitney 2006) and parents are usually the main decision-makers (Pyke-Grimm 2006) and strongly influence whether their child is involved or allowed to participate in SDM (Coyne 2010). The actual sequencing to how parent-child-professional participate in SDM is still not adequately described in any of the current research studies so there is a need for much more research in this area. It is important that children and parents are not seen as one actor as children's positions in decision-making could be undermined (Andre 2004). We need interventions that help support children's participation in SDM but which will also recognise and maintain family integrity (Coyne 2011b). The limited evidence on parents' perceptions of proxy decision-making indicates that parents find it challenging for many reasons (Jackson 2008; Young 2010). Perhaps the focus should be towards developing interventions targeted at parents and children so that parents can promote and support their child's participation in SDM.

There is strong support from policy makers for children's SDM but weak evidence about children's participation in SDM as this area of research is at an early stage and underdeveloped. It does seem to be the 'right' approach for clinicians to include children in SDM but we have no strong evidence that indicates which children desire inclusion, at what point in the trajectory of their treatment or illness, with whom do they want to share decision-making and about what topic.

AUTHORS' CONCLUSIONS

Implications for practice

This update of the review has highlighted the dearth of high-quality quantitative research on interventions to promote participation

in shared decision-making (SDM) for children with cancer. It remains unclear what factors promote the SDM approach and what interventions are effective and suitable for children. Based on the currently available evidence it is not possible to give recommendations for clinical practice.

Implications for research

More research is needed to investigate the effects of interventions that promote participation in SDM for children with cancer. New studies should be randomised controlled trials. Identifying such interventions will provide reassurance and guidance, and potentially contribute to successful communication between children, parents and the healthcare team. The interventions should be developed with the support of children and also should draw upon existing research, which reports the needs and preferences of children with cancer about SDM (Coyne 2010; Stegenga 2008). Research on SDM for children with other chronic illnesses may add useful information (Coyne 2011a; Miller 2012). Tailoring the interventions to children's preferences may help make the intervention more acceptable to children with cancer. SDM for children with cancer should be promoted as a positive end in itself rather than a means to achieve other ends desired by healthcare staff such as patient compliance.

Including children in healthcare SDM is an area that is relatively under-researched and underdeveloped but over time we should see more research occurring. Advances in technology will potentially lead to more developments of multi-media interventions to promote communication and SDM for children with chronic illnesses. A large number of patient decision aids has been developed for adults (Stacey 2014), and similar work needs to be done for children and young people. Studies are needed to identify how new multi-media innovations can support information exchange between children and healthcare professionals. Children are more familiar with new technologies and may prefer to receive information about their disease and treatments via an information technology medium (Suris 2010).

ACKNOWLEDGEMENTS

The Editorial Base of Cochrane Childhood Cancer is acknowledged for their advice and support. The editorial base of Cochrane Childhood Cancer is funded by 'Stichting Kinderen Kankervrij' (KIKa), the Netherlands. We would like to thank the Health Research Board Ireland for providing funding in the form of a two-year Cochrane Fellowship for the initial review. We also thank KIKa, the Netherlands, for the financial support which made it possible to perform this update.

REFERENCES

References to studies excluded from this review

Beale 2007 {published data only}

Beale IL, Kato PM, Marin-Bowling VM, Guthrie N, Cole SW. Improvement in cancer-related knowledge following use of a psychoeducational video game for adolescents and young adults with cancer. *Journal of Adolescent Health* 2007;**41**(3):263-70.

Dragone 2002 {published data only}

Dragone MA, Bush PJ, Jones JK, Bearison DJ, Kamani S. Development and evaluation of an interactive CD-ROM for children with leukaemia and their families. *Patient Education and Counselling* 2002;**46**(4):297-307.

Hollen 2013 {published data only}

Hollen PJ, Tyc VL, Donnangelo SF, Shannon SV, O'Laughlen MC, Hinton I, et al. A substance use decision aid for medically at-risk adolescents: results of a randomized controlled trial for cancer-surviving adolescents. *Cancer Nursing* 2013;**36**(5):355-67.

Jones 2010 {published data only}

Jones JK, Kamani SA, Bush PJ, Hennessy KA, Marfatia A, Shad AT. Development and evaluation of an educational interactive CD-ROM for teens with cancer. *Pediatric Blood & Cancer* 2010;**55**(3):512-9.

Kato 2008 {published data only}

Kato PM, Cole SW, Bradlyn AS, Pollack BH. A video game improves behavioral outcomes in adolescents and young adults with cancer: a randomized trial. *Pediatrics* 2008;**122**(2):e305-17.

Kurt 2011 {published data only}

Kurt AS, Savaser S. Short-term effects of remission video game in adolescents with cancer. *Psycho-Oncology* 2011;**20** (Suppl 2):30-104.

Additional references

Achenbach 1991

Achenbach T. Manual for the Child Behavior Checklist 4-18 and 1991 Profile. Burlington: University of Vermont Department of Psychiatry, 1991.

Alderson 2006

Alderson P, Sutcliffe K, Curtis K. Children as partners in their medical care. *Archives of Disease in Childhood* 2006;**91**:300-3.

Andre 2004

Andre N. Involving children in paediatric oncology decision-making. *Lancet Oncology* 2004;**5**:467.

Bandura 1977

Bandura A. Self-efficacy: toward a unifying theory of behavioral change. *Psychological Review* 1977;**84**:191-215.

Beck 1996

Beck AT, Steer RA, Brown GK. Manual for Beck Depression Inventory. 2nd Edition. San Antonio: Psychological Corporation, 1996.

Boylan 2004

Boylan P. Children and young people's views on health and health services: a review of the evidence. Children's Voices Project: Feedback from Children and Young People About their Experience and Expectations of Healthcare. London: Commission for Health Improvement, 2004.

Cavet 2005

Cavet J, Sloper P. Children and Young People's Views on Health and Health Services: a Review of the Evidence. London: National Children's Bureau, 2005.

Charles 1997

Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). *Social Science and Medicine* 1997;**44**(5):681-92.

Charles 1999

Charles C, Gafni A, Whelan T. Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model. *Social Science and Medicine* 1999;**49**:651-61.

Coyne 2006

Coyne IT, Hayes E, Gallagher P, Regan G. Giving children a voice: investigation of children's experiences of participation in consultation and decision-making in Irish hospitals. Giving Children a Voice: Investigation of Children's Experiences of Participation in Consultation and Decision-Making in Irish Hospitals. Dublin: Office of the Minister for Children, 2006.

Coyne 2010

Coyne I, Amory A, Kiernan G, Gibson F, Breatnach F. Children with Cancer: Children, Parents and Health Professionals' Perspectives on Children's Participation in Shared Decision-Making. Trinity College Dublin, Dublin. Dublin: Trinity College Dublin, 2010:1-149.

Coyne 2011a

Coyne I, Gallagher P. Participation in communication and decision-making: children and young people's experiences in a hospital setting. *Journal of Clinical Nursing* 2011;**20**(15-16):2334-43.

Coyne 2011b

Coyne I, Harder M. Children's participation in decision-making: balancing protection with shared decision-making using a situational perspective. *Journal of Child Health Care* 2011;**15**(4):312-9.

Coyne 2014

Coyne I, Amory A, Kiernan G, Gibson F. Children's participation in shared decision-making: children, adolescents, parents and healthcare professionals' perspectives and experiences. *European Journal of Oncology Nursing* 2014;**18**(3):273-80.

Coyne 2016

Coyne I, Amory A, Gibson F, Kiernan G. Information-sharing between healthcare professionals, parents and children with cancer: more than a matter of information exchange. *European Journal of Cancer Care* 2016;**25**(1):141-56.

De Winter 2002

De Winter M, Baerveldt C, Kooistra J. Enabling children: participation as a new perspective on child-health promotion. *Child Care Health and Development* 2002;**28**:109-16.

Degner 1992

Degner LF, Sloan JA. Decision making during serious illness: what role do patients really want to play. *Journal of Clinical Epidemiology* 1992;**45**(9):941-50.

Dy 2007

Dy SM. Instruments for evaluating shared medical decision making. *Medical Care Research and Review* 2007;**64**(6):623-49.

Edwards 2003

Edwards A, Elwyn G, Hood K, Robling M, Atwell C, Holmes-Rovner M. The development of COMRADE - a patient-based outcome measure to evaluate the effectiveness of risk communication and treatment decision making in consultations. *Patient Education and Counseling* 2003;**50**:311-22.

Elwyn 2003

Elwyn G, Edwards A, Wensing M, Atwell C, Grol R. Shared decision making: developing the OPTION scale for measuring patient involvement. *Quality and Safety in Health Care* 2003;**12**:93-9.

Elwyn 2005

Elwyn G, Hutchings H, Edwards A, Rapport F, Wensing M, Cheung WY, et al. The OPTION scale: measuring the extent that clinicians involve patients in decision-making tasks. *Health Expectations* 2005;**8**:34-42.

Elwyn 2006

Elwyn G, O'Connor A, Stacey D, Volk R, Edwards A, Coulter A, et al. Developing a quality criteria framework for patient decision aids: online international Delphi consensus process. *BMJ* 2006;**333**(7565):417.

Ende 1989

Ende J, Kazis L, Ash A, Moskowitz MA. Measuring patients' desire for autonomy; decision making and information-seeking preferences among medical patients. *Journal of General Internal Medicine* 1989;**4**(1):23-30.

Higgins 2011

Higgins JPT, Green S (editors). *Cochrane Handbook for Systematic Reviews of Interventions* Version 5.1.0 (updated March 2011). The Cochrane Collaboration, 2011. Available from www.cochrane-handbook.org.

Hinds 2001

Hinds P, Oakes L, Furman W, Quargnenti A, Olson MS, Foppiano P, et al. End-of-life decision making by adolescents,

parents, and healthcare providers in pediatric oncology. *Cancer Nursing* 2001;**24**(2):122-36.

Hinds 2005

Hinds P, Drew D, Oakes LL, Fouladi M, Spunt SL, Church C, et al. End-of-life care preferences of pediatric patients with cancer. *Journal of Clinical Oncology* 2005;**23**(36):9146-54.

Hokkanen 2004

Hokkanen H, Eriksson E, Ahonen O, Salanterä S. Adolescents with cancer: experience of life and how it could be made easier. *Cancer Nursing* 2004;**27**:325-35.

Hollen 1999

Hollen PJ, Hobbie WL, Finley SM. Testing the effects of a decision-making and risk reduction program for cancer-surviving adolescents. *Oncology Nursing Forum* 1999;**26**(9):1475-86.

Holmes-Rovner 1996

Holmes-Rovner MJ, Kroll N, Schmitt DR, Rovner ML, Breer ML, Rotherth G. Patient satisfaction with health care decisions: the satisfaction with decision scale. *Medical Decision Making* 1996;**16**(1):58-64.

Ishibashi 2001

Ishibashi A. The needs of children and adolescents with cancer for information and support. *Cancer Nursing* 2001;**24**(1):61-7.

Jackson 2008

Jackson C, Cheater FM, Reid I. A systematic review of decision support needs of parents making child health decisions. *Health Expectations* 2008;**11**:232-51.

Jemal 2009

Jemal A, Siegel R, Ward E, Hao Y, Xu J, Thun MJ. Cancer statistics 2009. *CA: A Cancer Journal for Clinicians* 2009;**59**(4):225-49.

Joosten 2008

Joosten EAG, DeFuentes-Merillas L, De Weert GH, Sensky T, van der Staak CPF, de Jong CAJ. Systematic review of the effects of shared decision-making on patient satisfaction, treatment adherence and health status. *Psychotherapy Psychosomatic* 2008;**77**:219-26.

Kremer 2016

Kremer LCM, Jellema P, Leclercq E, Noorman JK, van Dalen EC. Cochrane Childhood Cancer Group. About The Cochrane Collaboration (Cochrane Review Groups (CRGs)) 2016, Issue 1: Art. No.: CHILDCA.

Landgraf 1996

Landgraf JM, Abetz L, Ware JR. *Child Health Questionnaire (CHQ): a Users Manual*. Boston: The Health Institute, 1996.

Last 1996

Last BF, Van Veldhuisen AMH. Information about diagnosis and prognosis related to anxiety and depression in children with cancer aged 16 years. *European Journal of Cancer Care* 1996;**32A**(2):290-4.

Lerman 1990

Lerman CE, Brody DS, Caputo GC, Smith DG, Lazaro CG, Wolfson HG. Patients' perceived involvement in care scale: relationship to attitudes about illness and medical care. *Journal of General Internal Medicine* 1990;**5**(1):29-33.

Légaré 2014

Légaré F, Stacey D, Turcotte S, Cossi MJ, Kryworuchko J, Graham ID, et al. Interventions for improving the adoption of shared decision making by healthcare professionals. *Cochrane Database of Systematic Reviews* 2014, Issue 9. [DOI: [10.1002/14651858.CD006732.pub3](https://doi.org/10.1002/14651858.CD006732.pub3)]

Makoul 1998

Makoul G. Perpetuating passivity: reliance and reciprocal determinism in physician-patient interaction. *Journal of Health Communication* 1998;**3**:233-59.

Makoul 2006

Makoul G, Clayman ML. An integrative model of shared decision making in medical encounters. *Patient Education and Counseling* 2006;**60**:301-12.

McCabe 1996

McCabe MA. Involving children and adolescents in medical decision making: developmental and clinical considerations. *Journal of Pediatric Psychology* 1996;**21**:505-16.

McPherson 2006

McPherson AC, Glazebrook C, Forster D, James C, Smyth A. A randomized controlled trial of an interactive educational computer package for children with asthma. *Pediatrics* 2006;**117**:1046-54.

Miller 2012

Miller VA, Harris D. Measuring children's decision-making involvement regarding chronic illness management. *Journal of Pediatric Psychology* 2012;**37**:292-306.

Moore 2006

Moore JB, Kordick MF. Sources of conflict between families and health care professionals. *Journal of Pediatric Oncology Nursing* 2006;**23**(2):82-91.

Moore 2013

Moore PM, Rivera Mercado S, Grez Artigues M, Lawrie TA. Communication skills training for healthcare professionals working with people who have cancer. *Cochrane Database of Systematic Reviews* 2013, Issue 3. [DOI: [10.1002/14651858.CD003751.pub3](https://doi.org/10.1002/14651858.CD003751.pub3)]

O'Connor 1995

O'Connor AM. Validation of a Decisional Conflict Scale. *Medical Decision Making* 1995;**15**:25-30.

O'Connor 2005

O'Connor A, Llewellyn-Thomas H, Stacey D. International Patient Decision Aid Standards Collaboration. Background Document. ipdas.ohri.ca/IPDAS_Background.pdf (accessed 20 April 2013).

Pyke-Grimm 2006

Pyke-Grimm KA, Stewart JL, Kelly KP, Degner LF. Parents of children with cancer: factors influencing their treatment decision making roles. *Journal of Pediatric Nursing* 2006;**21**:350-61.

Ranmal 2008

Ranmal R, Prictor M, Scott JT. Interventions for improving communication with children and adolescents about their cancer. *Cochrane Database of Systematic Reviews* 2008, Issue 4. [DOI: [10.1002/14651858.CD002969.pub2](https://doi.org/10.1002/14651858.CD002969.pub2)]

RevMan 2014 [Computer program]

The Nordic Cochrane Centre, The Cochrane Collaboration. Review Manager (RevMan). Version 5.3. Copenhagen: The Nordic Cochrane Centre, The Cochrane Collaboration, 2014.

Roter 1991

Roter D. The Roter Method of Interaction Process Analysis. Baltimore: Johns Hopkins University, 1991.

Runeson 2002

Runeson I, Hallstrom I, Elander G, Hermeren G. Children's participation in the decision-making process during hospitalization: an observational study. *Nursing Ethics* 2002;**9**(6):583-98.

Scott 2003

Scott JT, Prictor MJ, Harmsen M, Broom A, Entwistle V, Sowden AJ, et al. Interventions for improving communication with children and adolescents about a family member's cancer. *Cochrane Database of Systematic Reviews* 2003, Issue 4. [DOI: [10.1002/14651858.CD004511](https://doi.org/10.1002/14651858.CD004511)]

Spielberger 1973

Spielberger C, Edwards C, Lushene R, Montuori J, Platzeck D. Preliminary Test Manual for the State-Trait Inventory for Children. Palo Alto: Consulting Psychologists Press, 1973.

Spinetta 2003

Spinetta JJ, Masera G, Jankovic M, Oppenheim D, Martins A, Arush WB, et al. Valid informed consent and participative decision-making in children with cancer and their parents: a report of the SIOP Working Committee on psychosocial issues in pediatric oncology. *Medical Pediatric Oncology* 2003;**40**:244-6.

Stacey 2014

Stacey D, Légaré F, Col NF, Bennett CL, Barry MJ, Eden KB, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systematic Reviews* 2014, Issue 1. [DOI: [10.1002/14651858.CD001431.pub4](https://doi.org/10.1002/14651858.CD001431.pub4)]

Stegenga 2008

Stegenga K, Ward-Smith P. The adolescent perspective on participation in treatment decision making: a pilot study. *Journal of Pediatric Oncology Nursing* 2008;**25**(2):112-7.

Suris 2010

Suris JC, Akre C, Berchtold A, Bélanger RE, Michaud PA. Chronically connected? Internet use among adolescents

with chronic conditions. *Journal of Adolescent Health* 2010;**46**(2):200-2.

Tates 2001

Tates K, Meeuwesen L. Doctor-parent-child communication: a review of the literature. *Social Science and Medicine* 2001;**52**:839-51.

Tates 2002

Tates K, Meeuwesen L, Bensing J, Elbers E. Affective and instrumental behaviour in doctor-parent-child communication. *Psychology and Health* 2002;**17**(3):281-95.

Tiffenberg 2000

Tiffenberg J, Wood E, Alonso A, Tossuti M, Vincente M. A randomized trial of ACINDES: a child centered training model for children with chronic illnesses (asthma and epilepsy). *Journal of Urban Health* 2000;**77**(2):280-97.

United Nations 1989

United Nations. United Nations Convention on the Rights of the Child. Geneva: United Nations, 1989.

Varni 2002

Varni JW, Burwinkle TM, Katz ER, Meeske K, Dickinson P. The PedsQL in pediatric cancer. *Cancer* 2002;**94**(7):2090-6.

Wallston 1978

Wallston KA, Wallston BS, DeVellis R. Development of the Multidimensional Health Locus of Control (MHLC) scales. *Health Education Monograph* 1978;**6**(2):160-70.

White 1996

White F. Parent-adolescent communication and adolescent decision-making. *Journal of Family Studies* 1996;**2**(1):41-56.

Whitney 2006

Whitney SN, Ethier AM, Fruge E, Berg S, McCullough LB, Hockenberry M. Decision making in pediatric oncology: who should take the lead? The decisional priority in pediatric oncology model. *Journal of Clinical Oncology* 2006;**24**:160-5.

Wicks 2010

Wicks L, Mitchell A. The adolescent cancer experience: loss of control and benefit finding. *European Journal of Cancer Care* 2010;**19**(6):778-785.

Wiering 2016

Wiering BM, Noordman J, Tates K, Zwaanswijk M, Elwyn G, de Bont ESJM, et al. Sharing decisions during diagnostic consultations; an observational study in pediatric oncology. *Patient Education and Counseling* 2016;**99**(1):61-7.

Wood 2010

Wood D, Turner G, Straw F. Not just a phase: a guide to the participation of children and young people in health services. *Royal College of Paediatrics and Child Health* 2010;**1**:1-53.

Young 2010

Young AJ, Kim L, Shu L, Baker JN, Schmidt M, Camp JM, et al. Research agency and communication challenges in discussions of informed consent in pediatric cancer. *Qualitative Health Research* 2010;**20**:628-43.

Zwaanswijk 2007

Zwaanswijk M, Tates K, Van Dulmen S, Hoogerbrugge PM, Kamps WA, Bensing JM. Young patients', parents', and survivors' communication preferences in paediatric oncology: results of online focus groups. *BMC Pediatrics* 2007;**7**(35):1-10.

Zwaanswijk 2011

Zwaanswijk M, Tates K, van Dulmen S, Hoogerbrugge P, Kamps WA, Beishuizen A, et al. Communicating with child patients in pediatric oncology consultations: a vignette study on child patients', parents', and survivors' communication preferences. *Psycho-Oncology* 2011;**20**:269-77.

References to other published versions of this review

Coyne 2011

Coyne I, O'Mathúna DP, Gibson F, Shields L, Sheaf G. Interventions for promoting participation in shared decision-making for children with cancer. *Cochrane Database of Systematic Reviews* 2011, Issue 2. [DOI: [10.1002/14651858.CD008970](https://doi.org/10.1002/14651858.CD008970)]

Coyne 2013

Coyne I, O'Mathúna DP, Gibson F, Shields L, Sheaf G. Interventions for promoting participation in shared decision-making for children with cancer. *Cochrane Database of Systematic Reviews* 2013, Issue 6. [DOI: [10.1002/14651858.CD008970.pub2](https://doi.org/10.1002/14651858.CD008970.pub2)]

CHARACTERISTICS OF STUDIES

Characteristics of excluded studies [ordered by study ID]

Study	Reason for exclusion
Beale 2007	Did not measure shared decision-making.
Dragone 2002	Did not measure shared decision-making.
Hollen 2013	Focus was on survivors of childhood cancer.

Study	Reason for exclusion
Jones 2010	Did not measure shared decision-making.
Kato 2008	Did not measure shared decision-making.
Kurt 2011	Did not measure shared decision-making.

APPENDICES

Appendix 1. Search strategy for Cochrane Central Register of Controlled Trials (CENTRAL)

1. For **decision making** the following text words were 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 aged 4-18 years** the following text words were 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* 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 were 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 hematoncolog* 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 was: 1 and 2 and 3

The search were performed in title, abstract or keywords.

[* = zero or more characters]

Appendix 2. Search strategy for PubMed (NLM)

1. For **decision making** the following MeSH headings and text words were 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 behavior* OR consensus OR consent* OR consumer* OR participation* OR cooperative behavior* OR co-operative behavior* 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 aged 4-18 years** the following MeSH headings and text words were 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 were 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 were used in the original review:

((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*)

For the update, the CCT part of the searches was widened:

((((random*[tiab] OR controlled[tiab]) 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 was: 1 AND 2 AND 3 AND 4

[Mesh Terms = PubMed Medical Subject Headings; Publication Type = PubMed publication type; tiab = title or abstract; * = zero or more characters]

Appendix 3. Search strategy for Embase (Ovid)

1. For **decision making** the following Emtree terms and text words were 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. (negotiat\$ 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 aged 4-18 years** the following Emtree terms and text words were 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 peadiatric\$).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 were 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 were 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\$) or (control\$ adj 5 trial\$)).mp.
9. exp PLACEBO/ or (placebo or placebos).mp.
10. or/1-9

The final combined search was: 1 AND 2 AND 3 AND 4

[mp = title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer name; \$ = zero or more characters; / = Emtree term; ti,ab = title or abstract; sh = subject heading; adj = adjacent]

Appendix 4. Search strategy for CINAHL (EBSCO)

1. For **decision making** the following CINAHL subject headings and text words were 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 aged 4-18 years** the following CINAHL subject headings and text words were 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 childs' 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 Tl 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 were 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 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 tumor's OR tumors OR tumors' OR tumorous OR tumour* OR wilms*)

4. For **RCTs/CCTs** the following CINAHL subject headings and text words were used in the original review:

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

For the update, the CCT part of the searches was widened:

((((random* OR controlled) 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 was: 1 AND 2 AND 3 AND 4

[AB = abstract; MH = CINAHL Heading; MH+ = CINAHL Heading (Exploded); TI = title; * = zero or more characters]

Appendix 5. Search strategy for ERIC (ProQuest)

This database changed platform from Dialog/Datastar to Dialog/ProQuest between the search suggested for the Protocol in February 2011 and the original review conducted in September 2012 - both sets of search strategies are provided. ProQuest remains the current database platform.

1. For **decision making**:

In February 2011 we proposed the following strategy:

(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 (attitude 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 (attitude 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 (attitude 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 (attitude OR attitudes)) OR (treatment AND refusal\$) OR uncertainty

The following ProQuest subject headings and text words were used both for the original version of the review and the update:

(SU.EXACT.EXPLODE("Decision Making" OR "Participative Decision Making") OR SU.EXACT.EXPLODE("Decision Making Skills")) 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 (attitude 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 (attitude 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 (attitude 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 (attitude OR attitudes)) OR (treatment AND refusal*) OR uncertainty)

2. For **children aged 4-18 years**:

In February 2011 we proposed the following strategy:

(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 paediatric\$ 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))

The following ProQuest subject headings and text words were used both for the original version of the review and the update:

(SU.EXACT.EXPLODE("African American Children" OR "Children" OR "Grandchildren" OR "Hospitalized Children" OR "Latchkey Children" OR "Migrant Children" OR "Minority Group Children" OR "Preadolescents" OR "Young Children") OR SU.EXACT.EXPLODE("Late Adolescents") OR SU.EXACT.EXPLODE("Early Adolescents") OR SU.EXACT.EXPLODE("Adolescents") 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 paediatric* 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 age") OR underage OR (youth OR youths)).

3. For **cancer and childhood cancer**:

In February 2011 we proposed the following strategy:

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 \$)

The following ProQuest subject headings and text words were used both for the original version of the review and the update:

(SU.EXACT.EXPLODE("Cancer") 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**:

In February 2011 we proposed the following strategy:

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

The following text words were used for the original version of the review:

((random* AND trial*) OR randomly OR randomized OR placebo*)

For the update, the CCT part of the searches was widened:

((random* OR controlled) AND trial*) OR randomly OR randomized OR placebo*)

The final combined search was: 1 AND 2 AND 3 AND 4

2011: [ADJ = adjacent; #.DE. = ERIC Thesaurus Descriptor; #.W..DE. = ERIC Thesaurus Descriptor (Exploded); \$ = zero or more characters]

2016 and 2012: [SU.EXACT.EXPLODE = ProQuest subject heading (exploded); * = zero or more characters]

Appendix 6. Search strategy for PsycINFO (EBSCO)

1. For **decision making** the following PsycINFO Thesaurus Descriptors subject headings and text words were 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 aged 4-18 years** the following PsycINFO Thesaurus Descriptors subject headings and text words were 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 childs' 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 text words were 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 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 tumor's OR tumors OR tumors' OR tumorous OR tumour* OR wilms*)

4. For **RCTs and CCTs** the following text words were used in the original review:

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

For the update, the CCT part of the searches was widened:

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

The final combined search was: 1 AND 2 AND 3 AND 4

[AB = abstract; DE = PsycINFO Thesaurus Descriptors; TI = title; * = zero or more characters]

Appendix 7. Search strategy for BIOSIS (Thomson Reuters)

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

TS=(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 TS=(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 aged 4-18 years** the following text words were used:

TS=(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* OR teen* OR under ag* OR underag* OR youth*)

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

TS=(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 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 tumor's OR tumors OR tumors* OR tumorous OR tumour* OR wilms*)

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

TS=((random* AND trial*) OR randomized OR randomly OR placebo*)

The final combined search was: 1 AND 2 AND 3 AND 4.

[TS = topic (searches in multiple fields including title and abstract); * = zero or more characters]

For the update, the BIOSIS search was not searched as subscription had ceased in December 2009.

Appendix 8. Search strategy for ProQuest Dissertations and Theses A&I (ProQuest)

The following text words were searched in the original review:

(cancer* OR neoplasm*) AND ((random* AND trial*) OR randomized OR randomly OR placebo*) AND (child* OR pediatric* OR paediatric*)

The search was run in all indexed fields, but not within the full text of theses.

For the update, the CCT part of the searches was widened:

(cancer* OR neoplasm*) AND (((random* OR controlled) AND trial*) OR randomized OR randomly OR placebo*) AND (child* OR pediatric* OR paediatric*)

Appendix 9. Search strategy for Sociological Abstracts (ProQuest)

This database had changed platform from Cambridge Scientific Abstracts to ProQuest between the search suggested for the Protocol in February 2011 and the original review conducted in September 2012, and search syntax between the original review and the updated search run in February 2016 - all relevant sets of search strategies are provided. ProQuest remains the current database platform.

1. For **decision making**:

In February 2011 we proposed the following strategy:

KW=(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)

For the original review we used the following strategy:

(SU.EXACT.EXPLODE("Decision Making" OR "Participative Decision Making") OR SU.EXACT.EXPLODE("Decision Making Skills") 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 (attitude 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 (attitude 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 (attitude 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 (attitude OR attitudes)) OR (treatment AND refusal*) OR uncertainty)

The following ProQuest subject headings and text words were used for the update:

(SU.EXACT("Participative Decision Making" OR "Group Decision Making" OR "Diagnosis" OR "Medical Decision Making" OR "Decision Making" OR "Participative Decision Making") 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 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 (attitude 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 (attitude 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 (attitude 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 (attitude OR attitudes)) OR (treatment AND refusal*) OR uncertainty)

2. For children aged 4-18 years:

In February 2011 we proposed the following strategy:

KW=(adoles* OR boy OR boys OR boyhood OR boyfriend OR child OR child's OR childs' 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 teen* OR under ag* OR underag* OR youth*)

For the original review we used the following strategy:

(SU.EXACT.EXPLODE("African American Children" OR "Children" OR "Grandchildren" OR "Hospitalized Children" OR "Latchkey Children" OR "Migrant Children" OR "Minority Group Children" OR "Preadolescents" OR "Young Children") OR SU.EXACT.EXPLODE("Late Adolescents") OR SU.EXACT.EXPLODE("Early Adolescents") OR SU.EXACT.EXPLODE("Adolescents") 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 age") OR underage OR (youth OR youths)))

The following ProQuest subject headings and text words were used for the update:

(SU.EXACT("African American Children" OR "Children" OR "Grandchildren" OR "Hospitalized Children" OR "Latchkey Children" OR "Migrant Children" OR "Minority Group Children" OR "Preadolescents" OR "Young Children" OR "Late Adolescents" OR "Early Adolescents" OR "Adolescents") 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**:

In February 2011 we proposed the following strategy:

KW=(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 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 tumor's OR tumors OR tumors' OR tumorous OR tumour* OR wilms*)

For the original review we used the following strategy:

(SU.EXACT.EXPLODE("Cancer") 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*))

The following ProQuest subject headings and text words were used for the update:

(SU.EXACT.EXPLODE("Cancer") 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**:

In February 2011 we proposed the following strategy:

KW=((random* AND trial*) OR randomized OR randomly OR placebo*)

For the original review we used the following strategy:

((random* AND trial*) OR randomly OR randomized OR placebo*)

For the update, the CCT part of the searches was widened:

((random* OR controlled) AND trial*) OR randomly OR randomized OR placebo*)

The final combined search was: 1 AND 2 AND 3 AND 4.

2011: [KW = keyword (searches title, abstract, descriptor and identifier fields); * = zero or more characters]

2016 and 2012: [SU.EXACT.EXPLODE = ProQuest subject heading (exploded); * = zero or more characters]

Appendix 10. Search strategy for conference proceedings

Child

Children

Young people

Adolescents

Shared decision making

Shared decision-making

Cancer

Appendix 11. Search strategy for ongoing trials databases

The following text words were used:

Child

Children

Young people

Adolescents

Shared decision making

Shared decision-making

Cancer

WHAT'S NEW

Date	Event	Description
29 February 2016	New citation required but conclusions have not changed	No eligible studies identified in this update of the review, so conclusions not changed.
29 February 2016	New search has been performed	The search for eligible studies was updated to 29 February 2016.

CONTRIBUTIONS OF AUTHORS

Conceiving, designing and co-ordinating the review: IC.

Performing previous work that was the foundation of the original review: IC.

Securing funding for the original review: IC.

Writing the protocol: IC.

Data collection for the review:

- designing search strategies: IC, EL, GS;
- undertaking searches: IC, EL, GS;
- screening search results: IC;
- selecting relevant references of included studies and relevant reviews for inclusion: IC, LS, FG;
- selecting studies from conference proceedings for inclusion in review or for studies awaiting assessment table: IC;
- organising retrieval of papers: IC;
- preparing data extraction form: IC, LS;
- screening retrieved papers against eligibility criteria: IC, DOM, LS;
- writing to authors of papers for additional information: IC;
- providing third-party arbitration for selection of studies: LS.

Writing the updated review: IC.

Reviewing the protocol and review: DOM, LS.

Providing general advice on the review: FG, DOM, LS.

All review authors approved the final version of the manuscript.

DECLARATIONS OF INTEREST

None.

SOURCES OF SUPPORT

Internal sources

- No sources of support supplied

External sources

- Stichting Kinderen Kankervrij (KIKa), Netherlands.

DIFFERENCES BETWEEN PROTOCOL AND REVIEW

For the update, we extended studies to be eligible from randomised controlled trials (RCTs) only, into RCTs and controlled clinical trials (CCTs). We searched for CCTs with retroactive effect. We would have used the most recent 'Risk of bias' criteria if eligible studies had been identified. It is a new policy of Cochrane Childhood Cancer to only perform sensitivity analysis when at least two studies remain in the analysis after high risk and unclear risk studies are excluded.

INDEX TERMS

Medical Subject Headings (MeSH)

*Decision Making; *Neoplasms; *Patient Participation

MeSH check words

Adolescent; Child; Child, Preschool; Humans