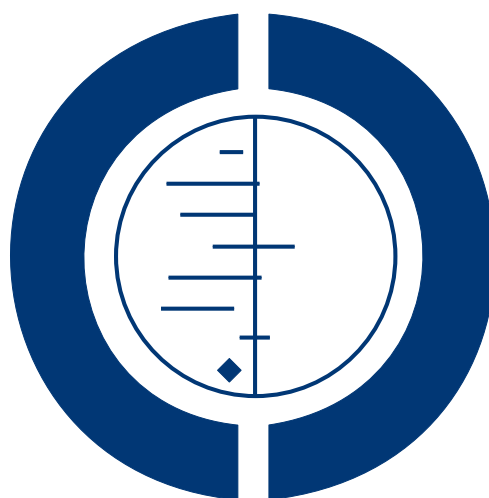


# Interventions for promoting participation in shared decision-making for children with cancer (Review)

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



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[Intervention Review]

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

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## ABSTRACT

### Background

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 shared decision-making (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: Cochrane Central Register of Controlled Trials (CENTRAL), *The Cochrane Library*, Issue 9, 2012); PubMed (1946 to September 2012); EMBASE (1974 to September 2012); CINAHL (1982 to September 2012); PsycINFO (1806 to September 2012); BIOSIS (1980 to December 2009 - subscription ceased at that date); ERIC (1966 to September 2012); ProQuest Dissertations and Theses (1637 to September 2012); and Sociological Abstracts (1952 to September 2012). We searched for information about trials not registered in these resources, either published or unpublished, by searching the reference lists of relevant articles and review articles and the following conference proceedings (2005-2012):

American Academy on Communication in Healthcare (AACH), European Society for Medical Oncology (ESMO), European Cancer Conference (ECCO), European Association for Communication in Healthcare (EACH), International Conference on Communication in Healthcare (ICCH), International Shared Decision Making Conference (ISDM 2005-2011 as held every two years), Annual Conference of the International Society for Paediatric Oncology (SIOP) and Annual Scientific Meeting of the Society for Medical Decision Making (SMDM).

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We searched the International Scientific and Technical Proceedings database (2005 to September 2012). We also searched Dissertation Abstracts (from 1980 to September 2012).

We scanned the ISRCTN (International Standard Randomized Controlled Trial Number) register and the National Institute of Health (NIH) Register for ongoing trials at: [www.controlled-trials.com](http://www.controlled-trials.com) and [clinicaltrials.gov](http://clinicaltrials.gov) on the 1 October 2012. We contacted authors for further details. We also contacted experts in this field.

We did not impose language restrictions.

### **Selection criteria**

Randomised controlled trials (RCTs) 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. We plan to expand the types of studies in future updates. Clearly more research is needed.

## **PLAIN LANGUAGE SUMMARY**

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

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 help them cope better with their cancer. The review of trials did not find any studies that helped children to participate in decision-making with parents and healthcare staff. More research is needed.

## **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 2011), decrease fears and concerns (Runeson 2002), increase adherence (De Winter 2002), reduce healthcare use (McPherson 2006) and promote satisfaction with health care (Alderson 2006; Freed 1998). 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). There is strong support from policy makers for children's shared decision-making (SDM) but weak evidence about children's participation in SDM as this area of research is young and underdeveloped.

### Childhood cancers

This review focused on 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 those 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). The International Society of Paediatric Oncology (SIOP) encourages doctors to share with children

developmentally relevant information that will improve their ability to participate in the decision-making process (Spinetta 2003). Information sharing is a prerequisite to SDM (Tates 2002a) but communication with children about their disease, treatment and care provision is often poorly performed in practice (Scott 2003).

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

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

There is currently no review of SDM interventions for children with cancer. However, there are three related systematic reviews that contribute useful background information. Moore 2004 assessed whether communication skills training is effective in changing health professionals' behaviour in cancer care with regard to communication and interaction with patients. Based on three trials, they concluded that labour-intensive communication skills training can have a beneficial effect on behaviour change in professionals working with people with cancer. Ranmal 2008 updated the Scott 2003 review of the effectiveness of interventions for improving communication with children and adolescents about their cancer. They concluded from 10 studies that weak evidence exists to suggest that some children and adolescents may derive some benefit from specific information-giving programmes and from interventions that aim to facilitate their reintegration in school and social activities. The interventions were directed towards communication generally rather than communication directed towards decision-making. O'Connor 2009 updated their 2003 review of decision aids for people facing health treatment or screening decisions. They concluded from 25 new studies that decision aids improve knowledge and realistic expectations, enhance active participation in decision-making, lower decisional conflict, decrease the proportion of people remaining undecided, and improve agreement between values and choices. Although this review showed that decision aids can assist in promoting decision-making, none of the studies included interventions for children with cancer.

### Description of the intervention

Any intervention for SDM for children with cancer. The interventions should focus primarily on children, but can also include 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 (SDM)

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

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

### How the intervention might work

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

## 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

Randomised controlled trials (RCTs) 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.

#### Types of participants

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

1. Children diagnosed with any type or stage of cancer; studies with children diagnosed with cancer who also have other illnesses were eligible.
2. Studies that involved parents or healthcare professionals, or both were eligible.
3. 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 sufficient studies were found to compare research decisions with clinical care decisions, but since no eligible studies were identified, 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

The primary outcome was SDM as measured with any validated scale. 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), 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 Behaviour 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).

The second primary outcome was measures of adverse effects.

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

### Secondary outcomes

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

- Measures of decisional quality (for example whether the patient 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 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

See: Cochrane Childhood Cancer Group methods used in reviews (Kremer 2010). We did not impose language restrictions.



## Electronic searches

We searched the following sources: Cochrane Central Register of Controlled Trials (CENTRAL), *The Cochrane Library*, Issue 9, (2012); PubMed (1946 to September 2012); EMBASE (1974 to September 2012); CINAHL (1982 to September 2012); PsycINFO (1806 to September 2012); BIOSIS (1980 to December 2009 - subscription ceased at that date); ERIC (1966 to September 2012); ProQuest Dissertations and Theses (1637 to September 2012); and Sociological Abstracts (1952 to September 2012).

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](#)).

## Searching other resources

We handsearched reference lists of relevant articles and the conference proceedings of the following (from 2005 to 2012): American Academy on Communication in Healthcare (AACH), European Society for Medical Oncology (ESMO), European Cancer Conference (ECCO), European Association for Communication in Healthcare (EACH), International Conference on Communication in Healthcare (ICCH), International Shared Decision Making Conference (ISDM 2005-2011 as held every two years), Annual Conference of the International Society for Paediatric Oncology (SIOP) and Annual Scientific Meeting of the Society for Medical Decision Making (SMDM). In relation to the conference proceedings that were not available online, contact was made with the Chairs of the following conferences: ISDM (2007 and 2009) and AACH (2006 and 2008), ICCH (2007, 2009) and EACH (2010). The Chairs and their colleagues who kindly provided assistance with retrieving conference proceedings were: Dr A Capellen, Dr Martin Harter, Dr Albert Mulley, Dr Sandra Van Dulmen, Gill Heaton, Sarah Dwinger, Marisa Greenberg, and Chris Pallozola. We searched the International Scientific and Technical Proceedings database (2005 to September 2012). We also searched Dissertation Abstracts (from 1980 to September 2012).

We scanned the ISRCTN (International Standard Randomized Controlled Trial Number) register and the National Institute of Health (NIH) Register for ongoing trials at: [www.controlled-trials.com](http://www.controlled-trials.com) and [clinicaltrials.gov](http://clinicaltrials.gov) on the 1 October 2012.

We also contacted the following authors for further details about their work on decision-making: Dr Cornelia Ruland and Professor Lesley Fallowfield.

We contacted people researching in this area and these were: Professor Pamela Hinds; Professor Roberta Woodgate; Professor Inger Hallström; Dr Kiek Tates; Professor Myra Bluebond-Langner; Professor Daniel Kelly; Professor Kathleen Ruccione; Professor Kathy Patterson Kelly; Dr Christina Baggott; and Dr Anders Cas-

tor. They did not suggest any additional studies than what we had already located in the electronic database searches.

## Data collection and analysis

### Selection of studies

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

1. We merged search results using reference management software (Endnote) and removed duplicate records of the same report.
2. 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.
3. The remaining abstracts (or an extract) were examined by two review authors and independently screened for applicability according to the following criteria: randomised trial, intervention, children aged four to 18 years, parents, healthcare professionals, and outcomes.
4. A third review author resolved any disagreements regarding selection of relevant studies and for full-text articles.
5. We retrieved full text of the potentially relevant reports.
6. 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](#)).
7. We examined full-text reports for compliance of studies with eligibility criteria.
8. We corresponded with investigators where appropriate to clarify study eligibility and to request missing data where necessary.
9. We did not find any studies that met the inclusion criteria for this review so we could not proceed to data extraction.

### Data extraction and management

Since we found no eligible studies for inclusion in this review, data extraction by two independent review authors using a standardised form could not be performed.

### Assessment of 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.

### Data synthesis

Since we found no eligible studies for inclusion in this review, data analyses could not be performed.



## RESULTS

### Description of studies

#### Results of the search

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 of the full-text articles that reported the four studies, 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 as yet. The author confirmed that the study did not measure the primary outcome of SDM. Three reviews were found from the electronic database search and we had copies of those already. These were: Joosten 2008; Ranmal 2008; and Scott 2003. No eligible studies were identified while screening the reference lists of these reviews.

The other searches did not yield any eligible studies for inclusion in this review.

#### Included studies

No eligible studies for inclusion in this review were identified.

#### Excluded studies

Two of the excluded papers were from the same study, which was a multi-site RCT of a psycho-educational intervention with adolescent and young adults with cancer (aged 13-29 years) (Beale 2007; Kato 2008). The psycho-educational 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 13-18 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 programs. 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 with a handbook (Jones 2010). We excluded these studies because they did not include SDM as an outcome.

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 who are aged four to 18 years.

## DISCUSSION

Unfortunately we did not find any eligible studies for inclusion in this review. The five studies that came closest to meeting the inclusion criteria of this review 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). The outcomes were: understanding, cancer-related knowledge, self efficacy, stress, and internal locus of control. 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).

It is clear that information exchange is a pre-requisite for participation in decision-making (Makoul 2006). 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 (Hokkanen 2004). Improvement in communication interactions may help children to become more familiar with healthcare professionals and to develop relationships with them. Having a good relationship with healthcare professionals may encourage children to participate in communication interactions (Dunsmore 1995). Feeling more prepared and comfortable interacting with healthcare professionals may encourage children to seek inclusion in the decision-making process, to ask more questions and express their preferences (Leveton 2008; Zwaanswijk 2007). However, Ranmal 2008 updated a review of interventions to improve communication with children and adolescents about their cancer and found that interventions to enhance communication have not been widely or rigorously assessed. They found studies that used the following interventions: computer-assisted education programme, CD-Rom about leukaemia, art therapy, group therapy, play and story-telling, and a self care coping intervention. They described the evidence as weak and recommended more research into the effects of these interventions and other related interventions. Interventions are needed both to improve communication and participation in decision-making.

Légaré 2010 reviewed the interventions for improving the adoption of SDM by healthcare professionals and concluded that the evidence was sparse and weak. They could not draw firm conclusions about the most effective types of interventions for increasing healthcare professionals' adoption of SDM. 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. Educational interventions that may increase healthcare professionals' awareness of children's need for inclusion in decisions could be useful. Légaré 2010 pointed out that implementation studies of SDM in clinical practice are increasing each year. Thus it is likely that there will be an increase in interventions that encourage healthcare professionals to adopt SDM. We did not find any interventions on SDM for healthcare professionals working in the area of childhood cancer, so more research is needed in this area.

In an update of the O'Connor 2009 review of decision aids for adults facing health treatment or screening decisions, Stacey 2012 found that decision aids combined with values clarification exercises improve knowledge of options, has a positive effect on patient-practitioner communication, and stimulates people to par-

ticipate more in decision-making. Stacey 2012 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 very 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 IPDAS Collaboration quality criteria on choice and the decision process (Elwyn 2006; O'Connor 2005). This review also suggests the 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. SDM can be complex, therefore SDM in chronic childhood illness may be easier as there are more chances to deliberate over decisions or to revisit decisions. In childhood cancer the treatment trajectory is complex and lengthy, therefore, efforts to include children in SDM may help children cope better with the illness. 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 prefer a collaborative role in that they want to be involved, consulted but not necessarily to have full responsibility for the decision made (Coyne 2011). Children should be involved as much as possible in decisions about their care, even when they are not able to make decisions on their own (Wood 2010). This concurs with current guidelines in paediatric oncology, which advocate that healthcare professionals encourage children to participate in medical decisions according to their developmental level (Spinetta 2003).

However, it is important to note that much of the evidence promoting children's participation is authored by policy makers and that we lack strong evidence from research that supports these recommendations. It does seem to be the 'right' approach for clinicians to include children in SDM but we do not have strong evidence that indicates which children desire inclusion, at what point in the trajectory of their treatment or illness, and with whom do they want to share decision-making and about what topic. Children sometimes prefer a passive role in SDM because they are too ill or distressed by the treatments. Likewise some children prefer

to hear information from their parents especially if it is 'bad' news or about treatment side effects (Coyne 2010). Decision-making in childhood cancer can be challenging (Whitney 2006) and parents are usually the main decision-makers (Pyke 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 position 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. 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.

## AUTHORS' CONCLUSIONS

### Implications for practice

This review has highlighted the dearth of high-quality quantitative research on interventions to promote participation in 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 RCTs. 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 2011; 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 multimedia interventions to promote communication and SDM for children with chronic illnesses. A large number of patient decision aids has been developed for adult patients (Stacey 2012) and similar work needs to be done for children and young people. Studies are needed into how new multimedia 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).

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## 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. [DOI: 10.1016/j.jadohealth.2007.04.006]

#### 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. [DOI: 11932129]

#### 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 and Cancer* 2010; **55**(3):512–19. [DOI: 10.1002/pbc.22608]

#### 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. [DOI: 10.1542/peds.2007-3134]

#### Kurt 2011 *{published data only}*

Kurt AS, Savaser S. Short-term effects of remission video game in adolescents with cancer. *Psycho-Oncology*. Wiley Online Library, 2011; Vol. 20 (Suppl 2):30–104. [DOI: 10.1002/pon.2077]

### 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. *The 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 2011

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.

#### 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.

#### Dixon-Woods 2002

Dixon-Woods M, Young B, Heney D. Childhood cancer and users' views: a critical perspective. *European Journal of Cancer Care* 2002; **11**:173–7.

#### Dunsmore 1995

Dunsmore J, Quine S. Information, support, and decision-making needs and preferences of adolescents with cancer: implications for health professionals. *Journal of Psychosocial Oncology* 1995; **13**:39–56.

**Dy 2007**

Dy SM. Instruments for evaluating shared medical decision making. *Medical Care Research and Review* 2007;**64**(6): 623–49. [DOI: 10.1177/1077558707305941]

**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 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. *British Medical Journal* 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.

**Freed 1998**

Freed LH, Ellen JM, Irwin CE, Millstein SG. Determinants of adolescent satisfaction with health care providers and intentions to keep follow-up appointments. *Journal of Adolescent Health* 1998;**22**:475–9.

**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](http://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, Rothert 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. [DOI: 10.1159/000126073]

**Kremer 2010**

Kremer LCM, van Dalen EC, Moher D, Caron HN. Childhood cancer group. In: *The Cochrane Library* 2010, (3):updated monthly.

**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.

**Leveton 2008**

Leveton M, Committee on Bioethics. Communicating with children and families: from everyday interactions to skill in conveying distressing information. *Pediatrics* 2008;**121**: e1441–60.

**Légaré 2010**

Légaré F, Ratté S, Stacey D, Kryworuchko J, Gravel K, Graham ID, et al. Interventions for improving the adoption of shared decision making by healthcare professionals. *Cochrane Database of Systematic Reviews* 2010, Issue 5. [DOI: 10.1002/14651858.CD006732.pub2]

**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. [DOI: 10.1016/j.pec.2005.06.010]

**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 2004**

Moore PM, Wilkinson SSM, Mercado SR. Communication skills training for health care professionals working with cancer patients, their families and/or carers. *Cochrane Database of Systematic Reviews* 2004, Issue 2. [DOI: 10.1002/14651858.CD003751.pub2]

**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.

**O'Connor 1995**

O'Connor AM. Validation of a decisional conflict scale. *Medical Decision Making* 1995;**15**:25–30. [DOI: 10.1177/0272989X9501500105]

**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](http://ipdas.ohri.ca/IPDAS_Background.pdf) (accessed 20 April 2013).

**O'Connor 2009**

O'Connor AM, Bennett CL, Stacey D, Barry M, Col NF, Eden KB, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systematic Reviews* 2009, Issue 3. [DOI: 10.1002/14651858.CD001431.pub2]

**Pyke 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]

**Roter 1991**

Roter D. *The Roter Method of Interaction Process Analysis*. Baltimore: John 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. [DOI: 10.1191/0969733002ne553oa]

**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]

**Spielberger 1973**

Spielberger C, Edwards C, Lushene R, Montuori J, Platzek 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 2012**

Stacey D, Bennett CL, Barry MJ, Eden KB, Holmes-Rovner M, Llewellyn-Thomas H, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systematic Reviews* 2012, Issue 5. [DOI: 10.1002/14651858.CD001431]

**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. [DOI: 10.1177/1043454208314515]

**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 2002a**

Tates K, Meeuwesen L. Doctor-parent-child communication: a review of the literature. *Social Science and Medicine* 2001;**52**:839–51. [S0277-9536(00)00193-3]

**Tates 2002b**

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. [DOI: 10.1080/08870440290029548]

**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.

**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. [ ISBN 978–1–906579–02–9]

**Young 2003**

Young B, Dixon-Woods M, Windridge KC, Heney D. Managing communication with young people who have a life threatening chronic illness: a qualitative study of patients and parents. *British Medical Journal* 2003;**326**:305–9.

**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. [DOI:: 10.1186/1471–2431–7–35]

**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. [DOI:: 10.1002/pon.1721]

**References to other published versions of this review****Coyne protocol 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]

\* Indicates the major publication for the study



## 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
Jones 2010	Did not measure shared decision-making
Kato 2008	Did not measure shared decision-making
Kurt 2011	Did not measure shared decision-making

## DATA AND ANALYSES

This review has no analyses.

## APPENDICES

### Appendix I. 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 behavior\* 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 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 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\*[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 hematocolog\* 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\*)

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 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 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 hematocolog\* OR hemato-oncolog\* OR hepatoblastom\* OR hepatom\* OR hodgkin\* OR leukaemi\* OR leukemi\* OR lymphom\* OR malignan\* OR medulloblastom\* OR meningiom\* OR neoplasm\* OR nephroblastom\* OR neuroblastom\* OR non-hodgkin\* OR oncolog\* OR osteosarcom\* OR PNET\* OR retinoblastom\* OR rhabdomyosarcom\* OR sarcom\* OR T-cell\* OR teratom\* OR tumor OR tumor's OR tumors OR tumors' OR tumorous OR tumour\* OR wilms\*)

4. For **RCTs/CCTs** the following MeSH headings and text words were used:  
((random\* AND trial\*[tiab]) OR "randomized"[tiab] OR "randomly"[tiab] OR "Randomized Controlled Trial"[Publication Type] OR "Controlled Clinical Trial"[Publication Type] OR "Randomized Controlled Trials as Topic"[Mesh Terms] OR "Placebos"[Mesh Terms] OR placebo\*)

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

[ tiab = title or abstract; sh = subheading\* = 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 behavio\$ or affective aspect\$ or cognitive aspect\$).mp.
  19. (health education or health information\$ or health literacy).mp. or exp health education/
  20. (patient participation or participation\$).mp. or exp patient participation/
  21. (consumer participation or consumer\$).mp. or exp consumer/
  22. (patient attitude or emotional aspect\$).mp. or exp patient attitude/
  23. physician attitude/ or physician attitude.mp.
  24. illness behavior.mp. or exp illness behavior/
  25. psychology.sh.
  26. attitude of health personnel.mp. or exp health personnel attitude/
  27. health knowledge.mp.
  28. (patient acceptance or patient adherence or patient attitude\$ or patient compliance or patient cooperation or patient co-operation).mp.
  29. (patient preference or patient involvement).mp.
  30. (patient education or patient satisfaction or patient involvement or patient non adherence or patient non compliance or patient nonadherence or patient non-adherence or patient noncompliance or patient non-compliance).mp.
  31. (decision aid or decision aids).mp.
  32. exp decision support system/
  33. (decision support system or decision support systems).mp.
  34. (Decision Support Technique or Decision Support Techniques).mp.
  35. (Decision Support Technic or Decision Support Technics).mp.
  36. (Decision Support Model or Decision Support Models).mp.
  37. (Decision Modeling or decision making or decision analysis or decision analyses).mp.
  38. (clinical support technique or clinical support techniques).mp.
  39. communication package.mp.
  40. (shared decision or shared decision making).mp.
  41. (shared decision or shared decisions).mp.
  42. (sharing decision or sharing decisions).mp.
  43. (informed choice or informed choices or informed decision\$).mp.
  44. (informed consent or informed assent or consensus or consent).mp. or exp informed consent/
  45. physician attitude.mp. or exp physician attitude/
  46. patient decision making.mp. or exp patient decision making/
  47. decision theory/ or decision theory.mp.
  48. educational technology.mp. or exp educational technology/
  49. (negotiati\$ or nursing role\$ or (nurs\$ and role\$)).mp.
  50. (psychosocial aspect\$ or psychosomatic aspect\$ or refusal participat\$ or shared decision\$ or sharing decision\$ or staff attitude\$ or treatment refusal\$ or uncertainty).mp.
  51. or/1-50
2. For **children 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\$).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 child's OR children\* OR girl\* OR highschool\* OR juvenil\* OR kid OR kids OR kindergar\* OR minors\* OR paediatric\* OR peadiatric\* OR pediatric\* OR prepuberty\* OR prepubescen\* OR preschool\* OR puber\* OR pubescen\* OR TI school\* OR AB school\* OR teen\* OR under ag\* OR underag\* OR youth\*)

3. For **cancer and childhood cancer** the following CINAHL subject headings and text words 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 hematocolog\* OR hemato-oncolog\* OR hepatoblastom\* OR hepatom\* OR hodgkin\* OR leukaemi\* OR leukemi\* OR lymphom\* OR malignan\* OR medulloblastom\* OR meningiom\* OR neoplasm\* OR nephroblastom\* OR neuroblastom\* OR non-hodgkin\* OR oncolog\* OR osteosarcom\* OR PNET\* OR retinoblastom\* OR rhabdomyosarcom\* OR sarcom\* OR T-cell\* OR teratom\* OR tumor OR tumor's OR tumors OR tumors' OR tumorous OR tumour\* OR wilms\*)

4. For **RCTs/CTTs** the following CINAHL subject headings and text words were used:

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

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

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

## Appendix 5. Search strategy for ERIC (ProQuest)

A number of databases changed providers between the search run in February 2011 and September 2012. In this case both sets of search strategies are provided. The name of the database provider given is the one current as of September 2012.

1. For **decision making** the following ProQuest subject headings and text words were used in September 2012:

(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 (atiitude OR attitudes)) OR (health AND education) OR (health AND information) OR (health AND literacy) OR (illness AND (behaviour OR behaviours OR behavioural OR behavior OR behaviors OR behavioral)) OR (informed AND assent) OR (informed AND choice\*) OR (informed AND decision\*) OR misinformation OR negotiati\* OR (nurse\* AND (role OR roles)) OR (patient\* AND acceptance) OR (patient\* AND adherence) OR (patient\* AND (attiitude 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 (attiitude 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 (attiitude OR attitudes)) OR (treatment AND refusal\*) OR uncertainty)

In February 2011 we used 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 (attiitude 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 negotiat\$ OR (nurse\$ AND (role OR roles)) OR (patient\$ AND acceptance) OR (patient\$ AND adherence) OR (patient\$ AND (attiitude 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 (attiitude 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 (attiitude OR attitudes)) OR (treatment AND refusal\$) OR uncertainty

2. For **children aged 4-18 years** the following ProQuest subject headings and text words were used in September 2012:

(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).

In February 2011 we used 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 peadiatric\$ OR pediatric\$ OR prepuberty\$ OR prepubescen\$ OR preschool\$ OR puber\$ OR pubescen\$ OR (school OR schools OR schooling OR schoolage OR schoolchild\$) OR teen\$ OR (under ADJ age) OR underage OR (youth OR youths))

3. For **cancer and childhood cancer** the following ProQuest subject headings and text words were used in September 2012:

(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 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 tumour\* OR wilms\*))

In February 2011 we used 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 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 tumour\$ OR wilms\$)

4. For **RCTs/CCTs** the following text words were used in September 2012:



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

In February 2011 we used the following strategy:

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

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

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

2011: [#.DE. = ERIC Thesaurus Descriptor; #.W..DE. = ERIC Thesaurus Descriptor (Exploded); ADJ = adjacent; \$ = 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 child's OR children\* OR girl\* OR highschool\* OR juvenil\* OR kid OR kids OR kindergar\* OR minors\* OR paediatric\* OR peditric\* 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 leukemi\* OR lymphom\* OR malignan\* OR medulloblastom\* OR meningiom\* OR neoplasm\* OR nephroblastom\* OR neuroblastom\* OR non-hodgkin\* OR oncolog\* OR osteosarcom\* OR PNET\* OR retinoblastom\* OR rhabdomyosarcom\* OR sarcom\* OR T-cell\* OR teratom\* OR tumor OR tumor's OR tumors OR tumors' OR tumorous OR tumour\* OR wilms\*)

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

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

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

(DE = PsycINFO Thesaurus Descriptors; TI = title; AB = abstract; \* = 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 behavior\* 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 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 paediatric\* 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 hematocolog\* OR hemato-oncolog\* OR hepatoblastom\* OR hepatom\* OR hodgkin\* OR leukaemi\* OR leukemi\* OR lymphom\* OR malignan\* OR medulloblastom\* OR meningiom\* OR neoplasm\* OR nephroblastom\* OR neuroblastom\* OR non-hodgkin\* OR oncolog\* OR osteosarcom\* OR PNET\* OR retinoblastom\* OR rhabdomyosarcom\* OR sarcom\* OR T-cell\* OR teratom\* OR tumor OR tumor's OR tumors OR tumors' OR tumorous OR tumour\* OR wilms\*)

4. For **RCTs 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]

## Appendix 8. Search strategy for ProQuest Dissertations and Theses (ProQuest)

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

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

## Appendix 9. Search strategy for Sociological Abstracts (ProQuest)

A number of databases changed providers between the search run in February 2011 and September 2012. In this case both sets of search strategies are provided. The name of the database provider given is the one current as of September 2012.

1. For **decision making** the following ProQuest subject headings and text words were used in September 2012:

(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\* AND patient 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)

In February 2011 we used 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 cooperative 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 negotiat\* 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 ProQuest subject headings and text words were used in September 2012:

(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)))

In February 2011 we used 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\*)

3. For **cancer and childhood cancer** the following ProQuest subject headings and text words were used in September 2012:

(SU.EXACT.EXPLODE("Cancer") OR (AML OR B-cell\* OR cancer OR cancer\* OR carcinom\* OR Ewing\* OR gliom\* OR hematolo\* OR hematocolog\* OR hemato-oncolog\* OR hepatoblastom\* OR hepatom\* OR hodgkin\* OR leukaemi\* OR leukemi\* OR lymphom\* OR malignan\* OR medulloblastom\* OR meningiom\* OR neoplasm\*) OR (nephroblastom\* OR neuroblastom\* OR non-hodgkin\* OR oncolog\* OR osteosarcom\* OR PNET\* OR retinoblastom\* OR rhabdomyosarcom\* OR sarcom\* OR T-cell\* OR teratom\* OR tumor\* OR tumour\* OR wilms\*))

In February 2011 we used 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 hematocolog\* OR hemato-oncolog\* OR hepatoblastom\* OR hepatom\* OR hodgkin\* OR leukaemi\* OR leukemi\* OR lymphom\* OR malignan\* OR medulloblastom\* OR meningiom\* OR neoplasm\* OR nephroblastom\* OR neuroblastom\* OR non-hodgkin\* OR oncolog\* OR osteosarcom\* OR PNET\* OR retinoblastom\* OR rhabdomyosarcom\* OR sarcom\* OR T-cell\* OR teratom\* OR tumor OR tumor's OR tumors OR tumors' OR tumorous OR tumour\* OR wilms\*)

4. For **RCTs/CCTs** the following text words were used in September 2012:

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

In February 2011 we used the following strategy:

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

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

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

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

## **CONTRIBUTIONS OF AUTHORS**

- Conceiving, designing, and co-ordinating the review: Imelda Coyne.
- Performing previous work that was the foundation of the current review: I Coyne.
- Securing funding for the review: I Coyne.
- Writing the protocol: I Coyne.
- Data collection for the review:
  - designing search strategies: I Coyne, G Sheaf;
  - undertaking searches: I Coyne, G Sheaf;
  - screening search results: I Coyne;
  - selecting relevant references of included studies and relevant reviews for inclusion: I Coyne, L Shields;
  - selecting studies from conference proceedings for inclusion in review or for studies awaiting assessment table: I Coyne;
  - organising retrieval of papers: I Coyne;
  - preparing data extraction form: I Coyne, L Shields;
  - screening retrieved papers against eligibility criteria: I Coyne, F Gibson, L Shields;
  - writing to authors of papers for additional information: I Coyne.
- Writing the review: I Coyne, L Shields.
- Reviewing the protocol and review: D O'Mathuna, L Shields.
- Providing general advice on the review: F Gibson, D O'Mathuna, L Shields.
- All authors approved the final version of the manuscript.

## **DECLARATIONS OF INTEREST**

None.

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