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[Intervention Protocol]

# Interventions for interpersonal communication about end of life care between health practitioners and affected people

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## ABSTRACT

This is a protocol for a Cochrane Review (Intervention). The objectives are as follows:

To assess the effects of interventions designed to improve verbal interpersonal communication about EoL care between health practitioners and people affected by EoL.

## BACKGROUND

### Description of the condition

Discussion about end of life (EoL) between health practitioners and affected people can be a confronting experience for all parties involved. According to the Australian Medical Association, "Death, dying and bereavement are all an integral part of life; however, reflecting on, and discussing death, can be profoundly confronting and difficult. Open and frank discussion of death and dying including EoL care options, approach to futile treatment, caring and bereavement should be encouraged within the profession and in the wider community" (AMA 2014). EoL and EoL

care can be defined in many different ways. For this review, we have adopted the following definitions, developed as part of a recent national (Australian) consensus statement on end of life care.

- End of life: "the period when a patient is living with, and impaired by, a fatal condition, even if the trajectory is ambiguous or unknown. This period may be years in the case of patients with chronic or malignant disease, or very brief in the case of patients who suffer acute and unexpected illnesses or events, such as sepsis, stroke or trauma" (ACSQHC 2015, p. 33).
- End of life care: "includes physical, spiritual and psychosocial assessment, and care and treatment delivered by health professionals and ancillary staff. It also includes support of families and carers, and care of the patient's body after their

death. People are 'approaching the end of life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:

- advanced, progressive, incurable conditions;
- general frailty and co-existing conditions that mean that they are expected to die within 12 months;
- existing conditions, if they are at risk of dying from a sudden acute crisis in their condition; and
- life-threatening acute conditions caused by sudden catastrophic events" (ACSQHC 2015, p. 33).

People involved in communication with health practitioners about EoL and EoL care may include the person at EoL and the family or carers of that person. Each of these people may have an important role in discussions about EoL care. For the purpose of this review, we need to define these different people in a way that is not ambiguous, given the multiplicity of terms that are used in different health systems for all parties. Further, although the term 'patient' is not always suitable for someone who may often not be in a patient role, we needed to distinguish the person at EoL from that person's family member or carer. We therefore define affected people as follows.

- Patient: identified as "the primary recipient of care" (ACSQHC 2015, p. 34). In many health systems and countries, terms other than 'patient' are preferred. However, in this review we use this term to distinguish clearly between people who are approaching the end of their life, or dying (and to whom discussions about prognosis, treatment, and care relate directly), and people to whom these discussions relate indirectly (i.e. discussions about EoL and EoL care related to a family member or person in whose care they are involved).

- Family: this review takes the broadest possible view of family members, considered to represent "those who are closest to the patient in knowledge, care and affection. This may include the biological family, the family of acquisition (related by marriage or contract), and the family and friends of choice" (ACSQHC 2015, p. 33).

- Carer: "a person who provides personal care, support and assistance to another individual who needs it because they have a disability, medical condition (including a terminal or chronic illness) or mental illness, or they are frail and aged. An individual is not a carer merely because they are a spouse, de facto partner, parent, child, other relative or guardian of an individual, or live with an individual who requires care" (ACSQHC 2015, p. 32).

EoL discussions are often placed within the context of palliative care. The "WHO [World Health Organization] identified that, globally, palliative care needs are very high, with an estimated 20 million people needing end-of-life care each year" (AIHW 2014, p. 2). This enormous demand exists across countries and healthcare systems (World Wide Palliative Care Alliance 2014), yet palliative

care is only one of the contexts in which good communication about EoL care is essential.

Internationally, a large body of research is documenting difficulties noted in EoL communication between healthcare professionals and people affected by EoL (i.e. patients, their families and carers) (Clayton 2007a; Fawole 2012; IoM 2014; NICE 2017; Walczak 2016). These difficulties include failure to communicate adequately with the person who is dying about his or her prognosis (Barnes 2006; Fawole 2012; Gott 2009; NICE 2017), or to provide understandable information on what the future holds and decisions that the person and family members and carers may need to make (Alsakson 2012; Anselm 2005; Barnes 2012; Gutierrez 2012; Selman 2007). It is also documented that EoL patients, or those closest to them, may not be given the opportunity to ask questions or to check their understanding of information that has been provided (Alsakson 2012; Clayton 2007a; Gutierrez 2012). People often have misunderstandings about their prognosis and goals of treatment in the EoL period (Clayton 2007a; Gattellari 1999; Weeks 1998). Misunderstandings may also arise from conflicting information given by multiple practitioners involved in the patient's care. Additionally, the patient and family members or carers may have their own questions about EoL care but may be unaware of how or whom they should approach to find answers to these questions (Alsakson 2012; Anselm 2005; Gutierrez 2012; NICE 2017).

Communication problems have significant potential to negatively impact the person who is dying and family members or carers. Communication problems may contribute to loss of trust in health practitioners (Clayton 2007a; NICE 2017), poorer quality of life and satisfaction, psychological harms, and avoidable distress (Chochinov 2000; Fawole 2012; NICE 2017; Schofield 2003; Selman 2007; Wright 2008). These negative outcomes reflect poorly on the ability of existing healthcare systems to effectively deliver patient-centred, responsive care during EoL (IoM 2014; NICE 2017). In comparison, high-quality communication about EoL has been associated with improved quality of life and less aggressive approaches to treatment, as well as better outcomes for carers related to bereavement (Detering 2010; Heyland 2009; Wright 2008; Zhang 2009).

Communicating effectively about EoL is a difficult and complex task that is further complicated by uncertainty about the trajectory of the last stages of a person's life (Barnes 2012; Fawole 2012). Good communication remains the primary means of preparing the patient and affected people for the last months, weeks, and days of life (Fawole 2012). This review focuses on general communication between health practitioners and people affected by EoL - not on communication involving use of specific tools to achieve structured decision-making (such as communication or discussion in which participants use a highly structured checklist to develop an advance care plan). With focus on general communication, this review is able to evaluate the evidence on interventions intended to improve communication about EoL care among health pro-

professionals and patients and family members and carers. Previous research has shown that discussion of prognosis and EoL is important to people who are dying and to their families (Steinhauser 2000; Walczak 2016; Wenrich 2001). It is clear that for people to be able to articulate what they would like, and to participate in decisions about their care in the last stages of their life or the life of someone close to them, they must be adequately informed (Clayton 2007a). A recent study seeking to develop quality indicators for EoL communication and decision-making confirmed that these discussions are also important to health professionals and the systems in which EoL care is delivered (Sinuff 2015). The highest-rated quality indicator overall was related directly to whether discussions about prognosis and the likelihood that the patient is approaching the end of life had actually been undertaken (Sinuff 2015). This review therefore seeks to evaluate how communication about EoL and EoL care might be better undertaken, and to assess the impact of verbal communication on the various people involved most directly.

## Description of the intervention

Communication interventions can be broadly defined as “a purposeful, planned and formalised strategy associated with a diverse range of intentions or aims, including to inform, educate, communicate with, support, skill, change behaviour, engage and seek participation of people” (Hill 2011, p. 30). This review follows this broad view and considers a communication intervention as a planned interaction provided by health practitioners to communicate with people about EoL and provision of EoL care. Although these interventions may take many forms and may reflect different purposes, to be eligible for this review interventions must include direct verbal communication between health practitioners and the patient and the patient’s family members and/or carers. Specifically, these interventions may take the form of facilitating or improving EoL care discussions targeting a broad range of continuum of care, ranging from rapidly evolving situations to early preparatory stages of what may be a protracted period of terminal care. The review will include any EoL communication intervention involving a patient who is likely to die within 12 months (ACSQHC 2015, p. 2; NICE 2017, p. 7). Communication interventions must be verbal in nature and preferably delivered in-person, although if necessary they may include the following channels for communication: in-person; telephone; videoconferencing; remote video links; and Internet-enabled verbal discussions.

The intervention may focus on one or more of the following elements of EoL or EoL care: knowledge of what might happen around the disease and what a possible disease trajectory might be for the patient (prognosis); understanding of the possibilities for treatment, pain management, symptom management, and treatment or care to relieve suffering; preferences for care and/or treatment, including wishes regarding the location of living until dying; needs or concerns related to supportive, spiritual, cultural, or

palliative care; needs or concerns related to the role of the family or carer, including support for family members/carers; needs or concerns associated with administrative paperwork, formal documentation, dying or the choice for assisted dying (for jurisdictions where relevant); and death. The intervention may be tailored towards an individual or a small group, as long as the group includes patients and their family members or carers.

We will consider the full range of EoL communication interventions identified as eligible for this review, and their dispersion and application across studies may vary. The needs and circumstances of the people involved will be complex and highly varied. Accordingly, the elements of EoL and EoL care to be discussed will be tailored to specific EoL contexts. EoL discussions are not limited to a specific healthcare setting, so it is important that this review is inclusive of EoL communication interventions applied irrespective of national, geographical, cultural, social, wealth, and healthcare access boundaries. Such diverse EoL experiences could be related to gender, ethnicity, race, religion, culture, refugee status, indigenous peoples, gender diversity, disability, socioeconomic status, education, poverty, and populations in low- and middle-income countries (Welch 2010). For this reason, this review will consider inequality and inequity issues as they relate to EoL communication interventions (Welch 2010).

## How the intervention might work

Interventions to improve EoL verbal communication aim to provide more effective general communication between practitioners and the people directly affected by EoL and EoL care. Previous reviews have confirmed the highly complex and varied scope of EoL experiences and support the need for the study intervention to be fully described and to include EoL context, details of what the intervention entails, and related primary patient outcomes (Fawole 2012; Walczak 2016).

We have described the content of the EoL communication intervention above. Practitioners could use a variety of modalities to deliver the intervention and to guide or influence the discussion about EoL or EoL care. Examples could include prompts for patients to promote or guide discussions about EoL care (Clayton 2007b; Walczak 2017); web-based collaboration tools to facilitate communication between practitioners and people affected by EoL (Voruganti 2017; Walczak 2016); nurse-led discussions about EoL care (Sulmasy 2017); or EoL family meetings (Agar 2017; Walczak 2016). Outcomes chosen to measure effects of the interventions could reflect changes in the level of communication occurring (e.g. increasing the frequency and/or length of discussions between practitioners and patients and affected people), improved structure of the communication taking place (e.g. providing prompts to assist patients, family members, and carers to ensure that key questions are raised with practitioners, thereby improving knowledge and understanding about EoL care), or specific outcomes re-

lated to patient's/affected people's EoL care experiences and their experiences of the communication around EoL.

### Why it is important to do this review

General EoL communication guidelines are already available. For example, in 2007, *Medical Journal of Australia* published a supplement titled "Clinical practice guidelines for communicating prognosis and end of life issues with adults in the advance stages in a life limiting illness, and their caregivers" (Clayton 2007a). More recently published EoL guidelines related to paediatric patients and young people include the "End of life planning series" (Together for Short Lives 2012), along with "Difficult Conversations" (Together for Short Lives 2015). EoL care standards and quality markers and measures of EoL care related to communication are also available (ACSQHC 2015; NICE 2017). A more recent exploratory study conducted with paediatric practitioners confirmed that evidence-based interdisciplinary interventions are needed to support general EoL discussions (Henderson 2017). A systematic review of communication quality improvement interventions for patients with advanced and serious illness completed in 2012 confirmed that better descriptions of communication interventions were needed for assessment of impact on the outcomes being researched (Fawole 2012). Although general guidelines on communication are available, they do not necessarily address or draw on rigorous research evidence related to the effectiveness of specific EoL communication interventions.

A systematic review and meta-analysis undertaken by Oczkowski in 2016 examined communication tools for EoL decision-making in ambulatory care settings (Oczkowski 2016). The Oczkowski review was focused on EoL decision-making and advance care planning and concluded that use of structured communication tools should be the preferred approach to EoL decision-making conversations (Oczkowski 2016). An existing Cochrane protocol - "Advance care planning for haemodialysis patients" - also has an indirect link with this review (Lim 2016). The current review will include discussions on the topic of advance care planning, but only when these conversations are taking place in the last 12 months of life, and only when uptake of advance care planning (ACP) or advance directives (AD) is not the primary goal of the study. Other Cochrane reviews - Chan 2016, "End-of-life care pathways for improving outcomes in caring for the dying"; Moore 2013, "Communication skills training for healthcare professionals working with people who have cancer"; and Shepperd 2016, "Hospital at home: home based end of life care" - have addressed issues related to EoL, but they have not addressed the *interventions to improve communication* that will be explored in this current review.

Previous reviews of the literature have considered EoL communication interventions. Barnes 2012 undertook a critical review of the literature to explore patient-professional communication about EoL issues in life-limiting conditions. These review authors found

limited evidence regarding successful interventions to improve discussions with patients about EoL care. Additionally, communication topics are often embedded in more specific EoL research. Walczak 2016 recently completed an important systematic review of evidence for EoL communication interventions. This review identified 45 studies through a search of the literature conducted in 2014, and review authors concluded that "Overall, greater use of validated measures, commonality of outcomes between studies and meta-analyses allowing more concrete statements about the efficacy of end-of-life communication interventions are vital to the advancement of the field" (Walczak 2016, p. 13). The literature reflects general agreement that EoL communication and interventions to improve such communication are important for providing quality care for patients and other people affected by EoL.

To inform how EoL communication can be improved in future practice, one must gain an understanding of the effectiveness of communication interventions in the EoL context and the impact these interventions can have on measurable outcomes for patients, families, and carers. The findings of this review should prove important in this endeavour. Improved and more effective communication between health practitioners and people affected by EoL has the potential to help practitioners address gaps in care, improve outcomes such as distress and poor quality of life associated with poor communication, and lay groundwork that will allow patients and others affected by EoL events to participate in decisions about treatment and care.

## OBJECTIVES

To assess the effects of interventions designed to improve verbal interpersonal communication about EoL care between health practitioners and people affected by EoL.

## METHODS

### Criteria for considering studies for this review

#### Types of studies

We will include randomised and cluster-randomised controlled trials (RCTs) and quasi-RCTs that evaluate the effects of interventions intended to enhance communication between health practitioners and patients and families or carers about EoL care. We expect to find a limited number of RCTs on this topic and therefore plan to include quasi-RCTs (defined as trials attempting, but not achieving, random allocation of participants).

## Types of participants

We will include the following participants.

- Patients with a life-limiting illness who are expected to die within 12 months (ACSQHC 2015).
- Patients with cancer, end-stage pulmonary disease, end-stage cardiac failure, end-stage renal failure, motor neuron disease, or other chronic conditions (e.g. dementia), as reported in the study.
- Patients with a life-threatening acute condition caused by sudden catastrophic events (ACSQHC 2015).
- Vulnerable groups of patients with a life-limiting illness, as reported in the study. For example, patients could be in a third world setting in which EoL is not explicitly defined. In such cases, researchers may use terms such as 'dying' and 'death', which can be used to identify the study as relevant.
- Patients of any age from birth who meet one of the criteria listed above.

We will also include family or carers of a patient with a life-limiting illness, as defined by the study. We define family as "biological, family of acquisition (related by marriage or contract) and the family and friends of choice" (ACSQHC 2015, p. 33). We define a carer as "a person providing personal care, support and assistance for the patient with a life-limiting illness" (ACSQHC 2015, p. 32).

We will not exclude studies based on the setting of the communication or the person delivering the communication, although the communication must involve a health practitioner. We define health practitioners to be included in this review as follows.

- Healthcare professionals may include doctors, nurses, midwives, allied health practitioners, social workers, and government healthcare workers.
- The professional population could be identified as the healthcare team, the interdisciplinary team, or a group of healthcare providers, as reported in the study.
- We may include lay health workers, who are not health practitioners as such but who are educated/trained to deliver the intervention (e.g. may be applicable in resource-poor/low- and middle-income country settings or within a specific cultural context to promote cultural safety).
- We may include other community providers or volunteers, as reported in the study.

## Types of interventions

We will include any interventions provided to promote or improve interpersonal communication between health practitioners and people affected by EoL care versus usual care. We will also include comparisons of one form of communication intervention versus another.

The communication may focus on any aspect of EoL or EoL care, including the following.

- Knowledge of what might happen around the disease and what a possible disease trajectory might be for the patient (prognosis).
- Understanding of the possibilities for treatment, pain management, symptom management, and treatment or care to relieve suffering.
- Preferences for care and/or treatment (e.g. resuscitation, feeding), including wishes regarding the location of living until dying.
- Needs or concerns related to supportive, spiritual, cultural, or palliative care.
- Needs or concerns related to the role of the family or carer, including support for family members/carers.
- Needs or concerns associated with administrative paperwork, formal documentation, and dying or the choice for assisted dying (for jurisdictions where relevant).

The intervention must involve interpersonal interaction between health practitioner(s) and the patient, family, and/or carers. We will include videoconferencing, remote video links, or Internet-enabled discussions only if the parties involved cannot be located physically together (e.g. in the case of patients living in rural, remote, or underserved areas).

The communication intervention might include one or more of the following aims: to inform or educate, support, skill, engage, or seek the participation of patients and their families and carers in a communication episode with professionals around EoL care. Interventions could be simple or complex; we will include interventions as long as the effects of the communication element of any complex intervention can be isolated by inclusion of an appropriate comparison group.

We will exclude the following studies.

- Studies focusing on specific decisions - shared or otherwise. This review will focus on general communication between health practitioners and patients and their family members and carers. Such communication may be viewed as a necessary and fundamental precursor to more specific decisions about treatment and other choices, which may often involve highly structured or specific communication tools (as described above).
- Studies focusing on development or completion of an ACP or AD for which uptake or completion is the primary outcome.
- Studies assessing the effects of public education (e.g. on ACP), or of general individual education (e.g. about ACP, or about how to speak up).
- Studies focusing on case conferencing for specific decision-making needs, or case conferencing about choice of residence (e.g. discharging patient to a nursing home or to a palliative care service).
- Studies focusing on communication skills training for health professionals (unless patient outcomes are reported as primary outcomes).



- Studies involving health practitioner communication with a group of people, unless that group comprises the patient, family members, and/or carers.

## Types of outcome measures

### Primary outcomes

#### Patient, family, and/or carer (affected persons) outcomes

- Knowledge and understanding about what might happen (prognosis), or what to do, or options.
- Evaluation of the communication - positive constructs (e.g. satisfaction, calmness or confidence about ability to manage the future).
- Evaluation of the communication - negative constructs (e.g. fear, anxiety, distress).
- Discussions of EoL care/EoL (e.g. frequency, length, type, participants).

#### Adverse outcomes

- Any adverse outcomes or harms identified in the included studies.
  - These might include any negative effects on the primary outcomes listed above.

#### Secondary outcomes

- Health practitioner knowledge and understanding of patient/family/carer knowledge, wishes, or preferences.
- Health practitioner evaluation of his or her communication performance, the overall communication encounter, or self-confidence or preparedness to communicate.
- Patient/family member/carer quality of life.

#### Health systems impacts relevant to the impacts of communication

- Costs of subsequent care.
- Hospital admissions and re-admissions (e.g. hospital bed days, intensive care unit (ICU) admissions).
- Quality of EoL care (family/carer rated, practitioner rated).
- Ratings of concordance with patient preferences for EoL care.

We will not exclude studies that are otherwise eligible based on the outcomes reported, except for the situation described above, in which the intervention focuses on ACP/AD and the primary outcome sought is uptake or completion.

### Main outcomes for the 'Summary of findings' tables

We will report the following outcomes.

#### Patient, family, and/or carer (affected persons) outcomes

- Knowledge and understanding about what might happen (prognosis), what to do, or options.
- Evaluation of the communication - positive constructs (e.g. satisfaction, calmness or confidence about ability to manage the future, preparedness to plan for the future).
- Evaluation of the communication - negative constructs (e.g. fear, anxiety, distress).

#### Adverse events

- These will be reported as any negative changes in the above outcomes associated with the intervention.

We will report findings for each of the primary outcomes in the 'Summary of findings' tables.

If multiple outcomes are reported in a given outcome category, we will collect information on all relevant outcomes. However, if the same outcome is assessed by two or more outcome measures in the same trial, two review authors will:

- select the primary outcome measure that has been identified by the publication authors;
- select the one specified in the sample size calculation when no primary outcome measure has been identified; and
- rank effect estimates (i.e. list them in order from largest to smallest) and select the median effect estimate if no sample size calculations are reported.
  - When an even number of outcome measures is reported, the outcome measure whose effect estimate is ranked  $n/2$ , where  $n$  is the number of outcome measures, will be selected.

### Search methods for identification of studies

#### Electronic searches

We will search the following electronic databases.

- Cochrane Central Register of Controlled Trials (CENTRAL; latest issue) in the Cochrane Library.
- MEDLINE (OvidSP) (inception to present).
- Embase (OvidSP) (inception to present).
- PsycINFO (OvidSP) (inception to present).
- Cumulative Index to Nursing and Allied Health Literature (CINAHL) (OvidSP) (inception to present).

We will present the strategy for MEDLINE (OvidSP) in [Appendix 1](#).

We will tailor strategies to other databases and report them in the review.



We will apply no language nor date restrictions.

### Searching other resources

We will contact experts in the field and authors of included studies for advice as to other relevant studies. We will also search reference lists of relevant studies. We will search grey literature sources including World Wide Hospice Palliative Care Alliance, TROVE, ProQuest Dissertations & Theses, British Library Electronic Theses Online Service (EThOS), and the Networked Digital Library of Theses and Dissertations (NDLTD). We will search clinicaltrials.gov to identify any relevant trials.

### Data collection and analysis

#### Selection of studies

Two review authors will independently screen all titles and abstracts identified through searches to determine which meet the inclusion criteria. We will retrieve in full text any papers identified as potentially relevant by at least one review author. Two review authors will independently screen full-text articles for inclusion or exclusion and will resolve discrepancies by discussion and by consultation with a third review author if necessary to reach consensus. We will list all potentially relevant papers excluded from the review at this stage as excluded studies and will provide reasons for exclusion in the 'Characteristics of excluded studies' table. We will also provide citation details and any available information about ongoing studies and will collate and report details of duplicate publications, so that each study (rather than each report) is the unit of interest in the review. We will report the screening and selection process in an adapted PRISMA flow chart (Liberati 2009).

#### Data extraction and management

Two review authors will extract data independently from included studies. We will resolve any discrepancies by discussion until consensus is reached, or through consultation with a third review author when necessary. We will develop and pilot a data extraction form using the Cochrane Consumers and Communication Group (CCCG) Data Extraction Template (available at <http://cccg.cochrane.org/author-resources>). Data to be extracted will include the following items: details of the study (aim of intervention, study design, description of the intervention and the comparison group, outcomes, and data). One review author will enter all extracted data into RevMan (Review Manager 2014), and a second review author working independently will check the data for accuracy against the data extraction sheets.

#### Assessment of risk of bias in included studies

We will assess and report on the methodological risk of bias of included studies in accordance with the *Cochrane Handbook for Systematic Reviews of Interventions* (Higgins 2011), as well as the guidelines of the Cochrane Consumers and Communication Review Group (Ryan 2013), which recommend explicit reporting of the following individual elements for RCTs: random sequence generation; allocation sequence concealment; blinding of participants and personnel; blinding of outcome assessment; completeness of outcome data; selective outcome reporting; and other sources of bias (baseline imbalances). We will consider blinding separately for different outcomes when appropriate (e.g. blinding may have the potential to differently affect subjective vs objective outcome measures). We will judge each item as being at high, low, or unclear risk of bias as set out in the criteria provided by Higgins 2011, and we will provide a quote from the study report and a justification for our judgement for each item in the risk of bias table.

We will judge studies to be at highest risk of bias if they are scored as at high or unclear risk of bias for either the sequence generation or the allocation concealment domain, based on growing empirical evidence that these factors are particularly important potential sources of bias (Higgins 2011).

In all cases, two review authors will independently assess the risk of bias of included studies and will resolve disagreements by discussion to reach consensus. We will contact study authors for additional information about the included studies, or for clarification of study methods as required. We will incorporate results of the risk of bias assessment into the review through standard tables and systematic narrative description and commentary about each of the elements, leading to an overall assessment of the risk of bias of included studies and a judgement about the internal validity of results of the review.

We will assess and report quasi-RCTs as being at high risk of bias on the random sequence generation item of the risk of bias tool. For cluster-RCTs, we will also assess and report the risk of bias associated with an additional domain: selective recruitment of cluster participants.

#### Measures of treatment effect

For dichotomous outcomes, we will analyse data based on the number of events and the number of people assessed in the intervention and comparison groups. We will use these numbers to calculate the risk ratio (RR) and the 95% confidence interval (CI). For continuous measures, we will analyse data based on the mean, the standard deviation (SD), and the number of people assessed for both intervention and comparison groups to calculate the mean difference (MD) and 95% CI. If the MD is reported without individual group data, we will use this information to report the study results. If more than one study measures the same outcome using different tools, we will calculate the standardised mean difference

(SMD) and the 95% CI using the inverse variance method in Review Manager 5.

### Unit of analysis issues

If cluster-RCTs are included, we will check for unit of analysis errors. If we find errors and sufficient information is available, we will re-analyse the data using the appropriate unit of analysis, by taking account of the intracluster correlation (ICC). We will obtain estimates of the ICC by contacting authors of included studies, or we will impute them using estimates from external sources. If it is not possible to obtain sufficient information to re-analyse the data, we will report effect estimates and will annotate the unit of analysis error.

### Dealing with missing data

We will attempt to contact study authors to obtain missing data (participant, outcome, or summary data). For participant data, we will, when possible, conduct analysis on an intention-to-treat basis; otherwise we will analyse data as reported. We will report on the levels of loss to follow-up and will assess this as a source of potential bias.

For missing outcome or summary data, we will impute missing data when possible and will report any assumptions in the review. We will investigate, through sensitivity analyses, the effects of any imputed data on pooled effect estimates.

### Assessment of heterogeneity

When we consider studies similar enough (based on consideration of populations, interventions, or other factors) to allow pooling of data using meta-analysis, we will assess the degree of heterogeneity by visually inspecting forest plots and by examining the  $\text{Chi}^2$  test for heterogeneity. We will quantify heterogeneity by using the  $I^2$  statistic. We will consider an  $I^2$  value of 50% or more to represent substantial levels of heterogeneity, but we will interpret this value in the light of size and direction of effects and strength of the evidence for heterogeneity, based on the P value derived from the  $\text{Chi}^2$  test (Higgins 2011).

When we detect substantial clinical, methodological, or statistical heterogeneity across included studies, we will not report pooled results from meta-analysis but will instead use a narrative approach to data synthesis. In this event, we will attempt to explore possible clinical or methodological reasons for this variation by grouping studies that are similar in terms of populations, intervention features, methodological features, or other factors to explore differences in intervention effects.

### Assessment of reporting biases

We will assess reporting bias qualitatively based on the characteristics of included studies (e.g. if only small studies that indicate positive findings are identified for inclusion); we will do this if information that we obtain upon contacting experts and study authors or studies suggests that there are relevant unpublished studies.

If we identify sufficient studies (at least 10) for inclusion in the review, we will construct a funnel plot to investigate small-study effects, which may indicate the presence of publication bias. We will formally test for funnel plot asymmetry, after choosing the test based on advice provided in Higgins 2011, and bearing in mind when interpreting study results that there may be several reasons for funnel plot asymmetry.

### Data synthesis

We will decide whether to meta-analyse data based on whether interventions in the included trials are similar enough in terms of participants, settings, interventions, comparisons, and outcome measures to ensure meaningful conclusions from a statistically pooled result. Owing to anticipated variability in populations and interventions, and possibly other factors, of included studies, we will use a random-effects model for meta-analysis.

If we are unable to pool the data statistically using meta-analysis, we will prepare a narrative synthesis of results. We will present major outcomes and results, organised by intervention categories according to major types and/or aims of identified interventions, or by other factors that we identify as key to effects of the interventions. Depending on the assembled research, we may also explore the possibility of organising the data by population. Within the data categories, we will explore the main comparisons of the review.

- Intervention versus usual care.
- One form of intervention versus another.

When studies compare more than one intervention, we will compare each intervention separately versus no intervention/control and versus another. If we are unable to pool the data statistically using meta-analysis, we will group data based on the category that best explores the heterogeneity of studies and makes the most sense to the reader (e.g. by interventions, populations, or outcomes). Within each category, we will present the data in tables and will narratively summarise and synthesise the results.

### Subgroup analysis and investigation of heterogeneity

We do not anticipate including enough studies with quantitative data to warrant subgroup analyses, but we will attempt to explore potential effects of the following factors through systematic grouping of studies and narrative synthesis when possible.

- Type of EoL care: groupings might include palliative care, acute (emergency) care, and others. The rationale for considering effects separately in such (or similar) groupings is that communication needs, opportunities to communicate, and

information and decisions needed are likely very different across such different types of EoL care.

- Type and/or aim of intervention: groupings might include those to inform and educate, those to support communication, and those to promote communication or decision-making skills. The rationale for separately considering these groupings is that interventions with different purposes have different underlying mechanisms of action.

### Sensitivity analysis

We do not expect to include enough studies in any one pooled analysis to justify conducting sensitivity analyses. However if we identify sufficient studies, we will consider removing those rated as having highest risk of bias from the analysis and examining effects on the pooled effect estimate.

### 'Summary of findings' table

We will prepare a 'Summary of findings' table to present results for the main outcomes, based on the methods described in Chapter 11 of the *Cochrane Handbook for Systematic Reviews of Interventions* (Schünemann 2011). We will present the results of analysis for major comparisons of the review, for each of the major primary outcomes, including potential harms, as outlined in the [Types of outcome measures](#) section. We will provide a source and rationale for each assumed risk cited in the table(s), and we will use the GRADE system to rank the quality of evidence using GRADE-

profiler (GRADEpro) software (GRADEpro GDT; Schünemann 2011). If meta-analysis is not possible, we will present results in a narrative 'Summary of findings' table format.

### Ensuring relevance to decisions in health care

One of the co-authors (JB) is a consumer representative for the Healthcare Consumers' Association of the Australian Capital Territory. She will have input to the protocol and will review it at all stages.

We also plan to consult more widely about the consumer perspective with consumer groups, industry, and/or government agencies. Subject to funding, we will conduct a focus group/s to evaluate the relevance of findings for practice. Participants could include representatives from stakeholders with content expertise in EoL care/practice.

A consumer will provide feedback on the protocol and the review as part of standard CCCG editorial processes.

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\* Indicates the major publication for the study

## APPENDICES

### Appendix I. MEDLINE search strategy

1. "Decision Support Techniques"/
2. exp Decision Support Systems, Clinical/
3. decision trees/
4. (decision making or choice behavior).mp. and informed consent.sh.
5. "Truth Disclosure"/
6. ((decision\* or decid\* or planning or choice\* or plans or plan or discuss\* or goal\* or directive\* or right\*) adj3 (support\* or aid\* or tool\* or instrument\* or technolog\* or technique\* or system\* or program\* or algorithm\* or process\* or method\* or intervention\* or material\* or conversation\* or share or shared or sharing or inform\* or making or behavior\*)).ti,ab,kw.
7. (decision adj (board\* or guide\* or counseling)).tw.
8. ((risk communication or risk assessment or risk information) adj4 (tool\* or method\*)).tw.
9. decision-making computer assisted/
10. (computer\* adj2 decision making).tw.
11. (communicati\* or discuss\* or ask\* or understand\*).ti,ab,kw.
12. (interactive adj (internet or online or graphic\* or booklet\*)).tw.
13. (interacti\* adj4 tool\*).tw.
14. ((interactiv\* or evidence based) adj3 (risk information or risk communication or risk presentation or risk graphic\*)).tw.
15. shared decision making.tw.
16. (informed adj (choice\* or decision\*)).tw.
17. adaptive conjoint analys#s.tw.
18. exp Decision Making/
19. exp Communication/
20. or/1-19
21. exp Advance Directives/
22. exp Advance Care Planning/
23. advanced care plan\*.ti,ab.
24. (advance\* adj2 directive\*).ti,ab.
25. living will\*.ti,ab.
26. exp Terminal Care/
27. "Terminally Ill"/
28. Palliative Care/
29. "Attitude to Death"/
30. (end of life or (life adj limit\*) or eol).ti,ab,kw.
31. (death or dies or die or dying or grief or bereav\* or palliati\*).ti,ab.

32. wills/
33. right to die/
34. patient self-determination act/
35. resuscitation orders/
36. advance directive adherence/
37. or/21-36
38. "Caregivers"/
39. "Interdisciplinary Communication"/
40. exp Community Participation/
41. Professional-Patient Relations/
42. "Physician-Patient Relations"/
43. "Professional-Family Relations"/
44. exp Family/
45. ((patient\$ or consumer\$ or family or families or relative\$ or parent\$ or child\$ or partner\$ or women\$ or carer\$ or caregiver\$ or advocate\$ or surrogate\* or subject\*) adj5 (activat\$ or involv\$ or communicat\* or initiat\$ or engag\$ or participat\$ or contribut\$ or collaborat\$ or role or cooperat\$ or assist\$ or champion\$ or advoc\$ or help-seek\$ or document\*)).tw.
46. exp legal guardians/
47. health care agent\*.tw.
48. power of attorney.tw.
49. proxy.tw.
50. or/38-49
51. end of life.tw.
52. (death or die or dies or dying).tw.
53. or/51-52
54. and/50,53
55. Patient Education as Topic/
56. Patient Preference/
57. or/54-56
58. randomized controlled trial.pt.
59. controlled clinical trial.pt.
60. randomized.ab.
61. placebo.ab.
62. drug therapy.fs.
63. randomly.ab.
64. trial.ab.
65. groups.ab.
66. Practice Guidelines as Topic/
67. Practice Guideline.pt.
68. or/58-67
69. exp animals/ not humans.sh.
70. 68 not 69
71. and/20,37,57,70



## CONTRIBUTIONS OF AUTHORS

AHenderson (guarantor for the review): conceived the review, planned and wrote the protocol.

RR: assisted with drafting the protocol.

SH: assisted with drafting the protocol.

JY: commented on the protocol.

NB: commented on the protocol.

JB: commented on the protocol.

AHerbert: commented on the protocol.

AHenderson will lead the review and all review authors will assist with different aspects of screening, data extraction, risk of bias assessment, and data entry to RevMan. AHenderson will lead drafting of the review with input from all other review authors.

## DECLARATIONS OF INTEREST

AHenderson: none known.

RR: completed this work as part of her role as editor with CCCG, funded by a Cochrane Infrastructure Grant provided by the National Health and Medical Research Council (NHMRC).

SH: none known.

JY: none known.

NB: none known.

JB: none known.

AHerbert: none known.

LP: none known.

## SOURCES OF SUPPORT

### Internal sources

- None, Other.

### External sources

- None, Other.

## NOTES

This protocol is based on standard text and guidance provided by the Cochrane Consumers and Communication Group ([CCCG 2016](#)).