



Evidence Summary 18-2 ARCHIVED

A Quality Initiative of the
Program in Evidence-Based Care (PEBC), Cancer Care Ontario (CCO)
Provider Tools for Advance Care Planning and Goals of Care
Discussions

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ARCHIVED

Provider Tools for Advance Care Planning and Goals of Care Discussions

Evidence Summary

THE PROGRAM IN EVIDENCE-BASED CARE

The Program in Evidence-Based Care (PEBC) is an initiative of the Ontario provincial cancer system, Cancer Care Ontario (CCO). The PEBC mandate is to improve the lives of Ontarians affected by cancer through the development, dissemination, and evaluation of evidence-based products designed to facilitate clinical, planning, and policy decisions about cancer control.

The PEBC is a provincial initiative of CCO supported by the Ontario Ministry of Health and Long-Term Care (OMHLTC). All work produced by the PEBC is editorially independent from the OMHLTC.

INTRODUCTION

Both Advance Care Planning (ACP) conversations and Goals of Care discussions (GoCD) involve the exploration of a person's values, beliefs, and what is most important to each person [1,2] to ensure concordance between the clinical care received by a person and the clinical care he or she has wished for. The context for each differs however, as ACP conversations focus on preparing for future healthcare decisions whereas GoCD focus on current healthcare decisions.

The purpose of ACP is to enable a person to express healthcare wishes with the aim that this information can be used by substitute decision maker(s) (SDMs) to guide future decision making if the person has become incapable. GoCD also facilitate decision making; however, more directly by either a person or their SDM at the time a decision is being made.

Despite the importance of ACP and GoCD, many healthcare providers are reluctant to engage patients in these dialogues. There have been several documented barriers to ACP and GoCD. Healthcare provider factors include the concerns of causing distress for a person or lessening hope, personal discomfort with death and dying, personal discomfort with their skills and knowledge related to these discussions, lack of experience in discussing end-of-life (EOL) issues, and lack of good mentorship [3,4]. Patient factors are also at play and include family's reluctance to address EOL issues, patients who are not ready to engage in these types of discussions, and difficulties if the patient is young [3,5]. Other important barriers include lack of guidelines and protocols around EOL issues as well as a lack of tools and training that could contribute to overcoming these barriers [3,5].

The objective of this evidence summary is to outline and summarize the evidence regarding existing healthcare provider tools and/or practices that address the processes for ACP or GoCD. Information about specific tools or approaches would then be available to Ontario providers for their use. It is important to acknowledge the inclusion of evidence that is not Ontario specific. This is important because of the significant variation in definition and implementation of both ACP and GoCD that relate to the different legal and regulatory environments. An example is found with advance directives (ADs), as these are not a legally recognized entity in Ontario. In Ontario, consent for a healthcare decision must come from a capable person (either the patient or SDM). Given these differences, the ACP and GoCD processes discussed in this paper may not reflect appropriate use in Ontario, and as such, the interventions may not be applicable. There may be effective elements of these practices, or approaches found to be beneficial that could be leveraged for use in Ontario. However, any

tools, resources, or interventions used in Ontario must align with the legal landscape, which includes reinforcing the connection to Health Care Consent. The Sponsoring Committee for this evidence summary was CCO's former Palliative Care Program.

RESEARCH QUESTIONS

These research questions were developed to direct the search for available evidence on tools that enable healthcare providers to introduce and facilitate ACP or GoCD as well as evidence for tools that will aid in documentation of these discussions.

- **QUESTION 1:** What tools enable providers to *introduce* advance care planning or goals of care discussions?
- **QUESTION 2:** What tools enable providers to *facilitate* advance care planning or goals of care discussions?
- **QUESTION 3:** What tools are best suited for *documentation* of advance care planning or goals of care discussions?

TARGET POPULATION

Healthcare providers who engage in ACP or GoCD with their patients or should engage in ACP or GoCDs with their patients.

INTENDED PURPOSE

To summarize the available evidence regarding provider tools for ACP or GoCD.

INTENDED USERS

Healthcare providers who engage in ACP or GoCD with their patients or should engage in ACP or GoCD with their patients and administrators who wish to provide ACP or GoCD training to providers within their institution.

METHODS

This evidence summary was developed by a Working Group, consisting of three family physicians that have an interest in palliative care and who hold palliative care positions within their communities, one family physician who practices comprehensive family medicine, one family physician with clinical focus areas in both emergency and hospitalist medicine, one clinician engagement lead, and one health research methodologist, at the request of CCO's former Palliative Care Program.

The Working Group was responsible for reviewing the identified evidence and drafting the summary. Conflict of interest declarations for all authors are summarized in Appendix 1, and were managed in accordance with the [PEBC Conflict of Interest Policy](#).

This evidence review was conducted in two planned stages, including a search for systematic reviews followed by a search for primary literature. These stages are described in subsequent sections.

Search for Existing Guidelines and Systematic Reviews

A search was conducted for existing guidelines and systematic reviews from 2010 onwards. The MEDLINE (2010 to June 2015) and EMBASE (2010 to week 26, 2015) databases were searched using the literature search strategy found in Appendices 2 and 3. Guidelines

and systematic reviews were included if they were published in English, were directly related to one or more of the guideline questions, and reported at least one outcome of interest.

Identified systematic reviews were evaluated based on their clinical content and relevance. Relevant systematic reviews were assessed using the 11-item Assessment of Multiple Systematic Reviews (AMSTAR) [6] tool to determine whether or not existing systematic reviews met a minimum threshold for methodological quality and could be considered for inclusion in the evidence base.

Search for Primary Literature

A search strategy was developed and implemented that captured the primary literature in the following databases: MEDLINE, EMBASE, and American Society for Clinical Oncology (ASCO) Palliative Care Symposium meeting abstracts.

Literature Search Strategy

The MEDLINE (1998 to September 2015) and EMBASE (1998 to week 37, 2015) databases were searched using the literature search strategies found in Appendix 4. In addition, ASCO Palliative Care Symposium for 2014 and 2015 were also searched using the following terms: advance care planning or ACP, goals of care or GoC, advance directives or AD, terminal care, and patient care planning. Reference lists of included studies were also searched.

Study Selection Criteria and Process

Inclusion Criteria

- English language
- Patients living with chronic illnesses and/or their substitute decision makers OR simulated patients
- Healthcare provider tools (as opposed to patient tools)
- Includes at least one outcome of interest (see Appendix 5)
- Comparative data (randomized trials, cohort, case-controlled, historically controlled trials, etc.) if available
- Non-comparative data
- Minimum study size of 30 patients

Exclusion Criteria

- Case studies, commentaries, editorials

A review of the titles and abstracts that resulted from the search was conducted independently by one reviewer (RC). For items that warranted full-text review, one reviewer (RC) reviewed each item independently. However, if there was any uncertainty regarding a particular paper, the Working Group was consulted.

Data Extraction and Assessment of Study Quality and Potential for Bias

Data from the included studies were extracted by one member of the Working Group (RC). All extracted data and information were audited by an independent auditor.

Randomized controlled trials (RCTs) were assessed using the Cochrane Risk of Bias tool (chapter 8.5) (<http://handbook.cochrane.org/>) and all non-RCTs were assessed using the Cochrane Risk Of Bias In Non-Randomized Studies - of Interventions (ROBINS-I) tool (<https://sites.google.com/site/riskofbiastool/>).

Synthesizing the Evidence

Meta-analysis was not planned as the studies included in this systematic review were quite varied and included some non-comparative data.

RESULTS

Search for Existing Guidelines and Systematic Reviews

A search for guidelines uncovered 1701 documents. Of these, 82 papers (73 adult and nine pediatric) underwent full-text review. No adult guidelines were retained and one pediatric guideline was retained.

A search for systematic reviews yielded 824 documents. Of these, 55 papers (47 adult and eight pediatric) underwent full-text review. No adult systematic reviews were retained and one pediatric systematic review was retained.

Search for Primary Literature

A search for primary literature was conducted for all guideline questions.

Literature Search Results

A search for primary studies yielded 31,105 documents. Of these, 353 (313 adult and 40 pediatric) underwent full text-review. From this, 34 adult studies represented by 36 papers and three pediatric primary studies represented by four papers were retained. In addition, the abstracts from the 2014 and 2015 ASCO Palliative Care in Oncology symposia were searched, resulting in the retention of one abstract of adult ACP. A search of the reference lists of included studies led to the inclusion of a further seven adult studies. For a summary of the full literature search results (including guidelines and systematic reviews), please refer to Figure 1, which is a flow diagram depicting the inclusion and exclusion of all studies for this evidence document. A summary of all included studies can be found in Table 1.

Of the 42 included adult primary studies, 10 were RCTs, seven were pre/post designs and four were controlled trials. There were three studies each of the following types of designs: repeated measures, qualitative, chart reviews, and non-comparative studies. There was one or two each of various other study types including one systematic review, which was identified from the search for primary studies and not the search for systematic reviews. Of the three included pediatric primary studies, one was a RCT, one was a survey, and one was a chart review.

Figure 1. Literature search results flow diagram.

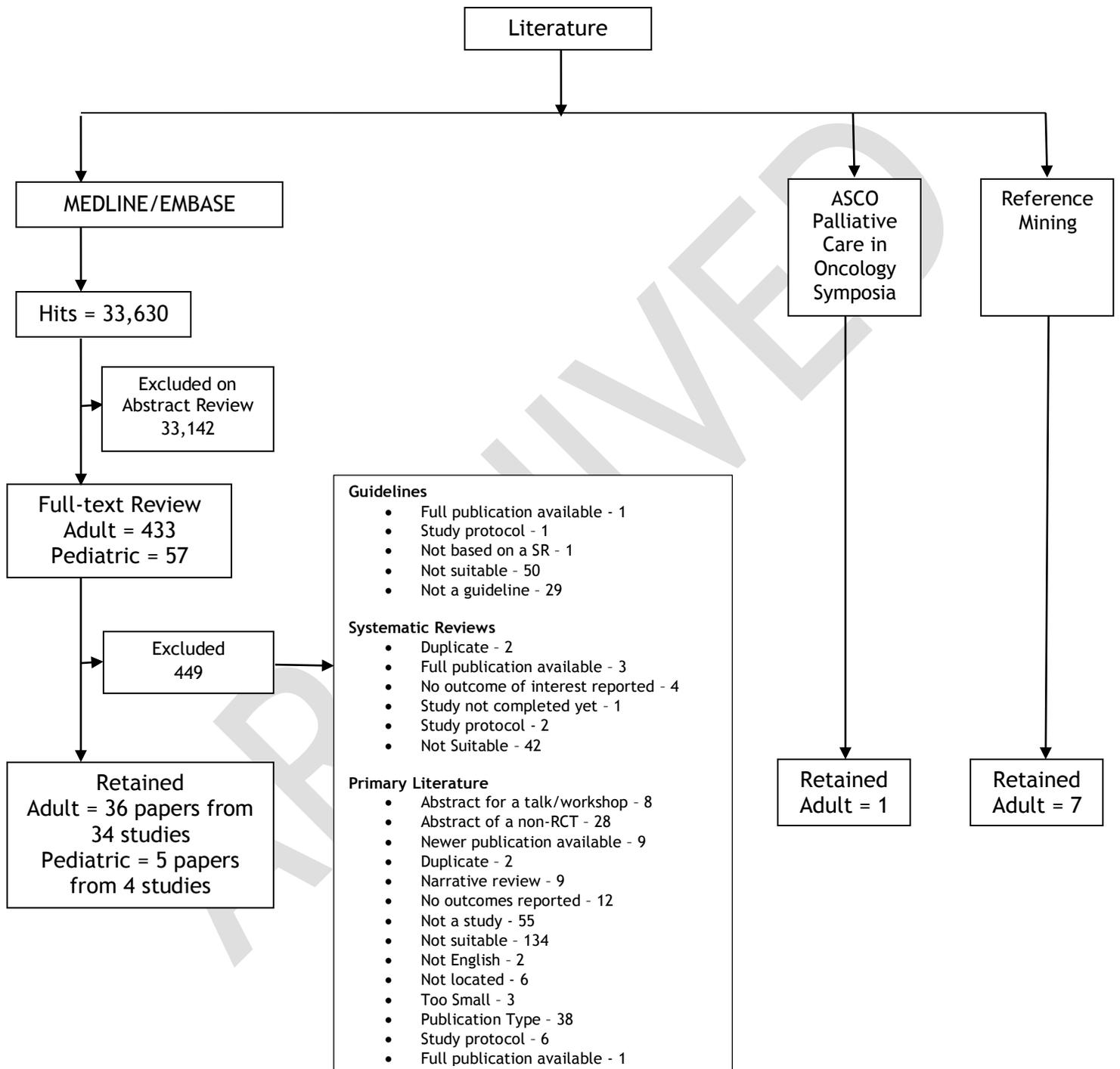


Table 1. Studies selected for inclusion.

Study	Tool Name	Study Type
ADULT STUDIES		
Boettcher 2015 [7]	Respecting Choices	Repeated Measures
Davis 2015 [8]	Conversation Project	Qualitative Evaluation
Hickman 2015 [9]	POLST	Systematic Review
Kadlec 2015 [10]	Practice Support Program - EOL Module	Repeated Measures
Detering 2014 [11]	Next Steps	Pre/Post Study
Paladino 2014 [12] <i>abstract</i>	Serious Illness Conversation Guide	Cluster RCT
Pecanac 2014 [13]	Respecting Choices	Chart Review
Slort 2014a [14]	ACA	Controlled Trial
Slort 2014b [15]	ACA	Controlled Trial
Wheeler 2014 [16]	Foundation in EOL/Palliative Care	Pre/Post Study
Wilson 2014 [17]	HCM	Non-comparative
Abel 2013 [18]	Planning Ahead	Retrospective Cohort
Levi 2013 [19]	MYWK	Qualitative Evaluation
Millington-Sanders 2013 [20]	Coordinate My Care	Non-comparative
Slort 2013 [21]	ACA	Controlled Trial
Wilson 2013 [22]	EpicCare HER	Chart Review
Au 2012 [23]	NA	Cluster-RCT
Clayton 2012 [24]	PREPARED	Pre/Post Study
Colville 2012 [25]	NA	Descriptive Qualitative Study
Green 2011 [26]	MYWK	RCT
Resnick 2011 [27]	NA	Survey
Detering 2010 [2]	Respecting Choices	RCT
Hammes 2010 [28]	Respecting Choices	Chart Review
Kirchhoff 2010/2012 [29,30]	PC-ACP	RCT
Szmulowicz 2010 [31]	NA	RCT
Newton 2009 [32]	Preferred Priorities of Care	Non-comparative
Hales 2008 [33]	NA	Pre/Post Study
Runkle 2008 [34]	Four Habits Approach	Repeated Measures
Alexander 2006 [35]	PREPARE	Prospective Controlled Trial
Lorin 2006 [36]	NA	Prospective Comparison
Zapka 2006a [37]	NA	Pre/Post Study
Zapka 2006b [38]	NA	Pre/Post Study
Pearlman 2005 [39]	Your Life, Your Choices	RCT
Song 2005 [40]	PC-ACP	RCT
Wisow 2004 [41]	NA	Prospective, Quasi-experimental
Ahrens 2003 [42]	NA	Prospective Comparison
Bricker 2003 [43]	NA	Descriptive
Schwartz 2002 [44]	Respecting Choices	RCT
Pauls 2001 [45]	NA	Descriptive
Ratner 2001 [46]	Kitchen Table Discussion	Case Series
Tierney 2001/Dexter 1998 [47,48]	Computer generated reminders	2x2 factorial RCT
Railey 1999 [49]	NA	Pre/Post Study
PEDIATRIC STUDIES		
Lyon 2014/2013 [50,51]	FACE-TC	RCT
Lotz 2013 [52]	FACE, Footprints, Respecting Choices	Systematic Review
Mitchell 2013 [53]	NA	Survey
Walter 2013 [54]	PGOCC	Chart Review

ACA=availability, current issues and Anticipation; EOL=end of life; FACE=Family-Centered Advance Care Planning; FACE-TC=Family-Centered Advance Care Planning for Teens with Cancer; HCM=Honoring Choices Minnesota; MYWK=Making Your Wishes Known; NA=not applicable; PC-ACP=patient-centred advance care planning; PGOCC=prognostic goals-of-care conversation; POLST= Physician Orders for Life-Sustaining Treatment; PREPARE=Program of Resident Education to Promote Awareness and Respect at the End of life; RCT=randomized controlled trial.

Study Design and Quality

Various study designs are included in this guidance document. All systematic reviews were assessed using AMSTAR [6] (see Table 2). Randomized controlled trials were assessed using the Cochrane Risk of Bias tool (chapter 8.5) (<http://handbook.cochrane.org/>) (see Table 3) and all non-RCTs were assessed using Risk Of Bias In Non-Randomized Studies - of Interventions (ROBINS-I) tool (<https://sites.google.com/site/riskofbiastool/>) (see Table 4).

Guidelines

No suitable guideline was identified.

Systematic Reviews

All systematic reviews used in this guidance document were assessed using the AMSTAR tool [6]. Both systematic reviews provided an a priori design, conducted duplicate study selection and data extraction, performed a comprehensive literature search, provided the characteristics of each included study, combined the findings of the included studies appropriately (e.g., by not combining), and provided conflict of interest statements. (Table 2).

Table 2: Evaluation of included systematic reviews using AMSTAR.

ITEM	Hickman 2015 [9]	Lotz 2013 [52]
1. Was an 'a priori' design provided?	Y	Y
2. Was there duplicate study selection and data extraction?	Y	Y
3. Was a comprehensive literature search performed?	Y	Y
4. Was the status of publication (i.e., grey literature) used as an inclusion criterion?	N	N
5. Was a list of studies (included and excluded) provided?	N	N
6. Were the characteristics of the included studies provided?	Y	Y
7. Was the scientific quality of the included studies assessed and documented?	N	N
8. Was the scientific quality of the included studies used appropriately in formulating conclusions?	N	N
9. Were the methods used to combine the findings of the studies appropriate?	Y	Y
10. Was the likelihood of publication bias assessed?	NA	N
11. Was the conflict of interest stated?	Y	Y
TOTAL AMSTAR POINTS	6	6

N = no; NA = not applicable; Y = yes

Randomized Controlled Trials

Eleven RCTs reported in 14 papers [2,12,23,26,29-31,39,40,44,47,48,50,51] were included in this guidance document and were assessed using Cochrane's Risk of Bias tool (chapter 8.5) (<http://handbook.cochrane.org/>) (Table 3). Paladino et al. [12] was only available in abstract form; therefore, risk of bias was unclear because the needed information was not available in the abstract. Six other trials [23,26,39,40,47,48,50,51] had overall high risks of bias owing to several items being rated as either high risk of bias or unclear risk of bias. Unclear risk of bias may only be a reporting issue; however, it is impossible to know.

Table 3: Evaluation of included randomized controlled trials using Cochrane's Risk of Bias tool.

Study	SELECTION BIAS		PERFORMANCE BIAS	DETECTION BIAS	ATTRITION BIAS	REPORTING BIAS	OTHER BIAS
	Random Sequence Generation	Allocation Concealment	Blinding of Participants and Personnel	Blinding of Outcome Assessment	Incomplete Outcome Data	Selective Reporting	Other Sources of Bias
ADULT TRIALS							
Paladino 2014 [12] <i>abstract</i>	Unclear	Unclear	Unclear	Unclear	Unclear	Unclear	Unclear
Au 2012 [23]	Unclear	Unclear	High	Low	Low	Low	High
Kirchhoff 2012/2010 [29,30]	Low	Low	High	Unclear	Low	Low	Low
Green 2011 [26]	Unclear	Unclear	High	Unclear	Low	Low	Low
Detering 2010 [2]	Low	Low	High	Low	Low	Low	Low
Szmulowicz 2010 [31]	Low	Low	High	Low	Low	Low	Low
Pearlman 2005 [39]	Low	Unclear	High	Unclear	Unclear	Low	Low
Song 2005 [40]	Unclear	Unclear	High	Unclear	Low	Low	Low
Schwartz 2002 [44]	Low	Low	High	Unclear	Low	Low	Low
Tierney 2001 /Dexter 1998[47,48]	Low	Unclear	High	Unclear	Unclear	Low	Low
PEDIATRIC TRIALS							
Lyon 2014/2013 [50,51]	Unclear	Unclear	High	High	Low	Low	Low

Non-Randomized Controlled Studies

This guidance document included 33 non-RCTs, which were each assessed using Risk Of Bias In Non-Randomized Studies - of Interventions (ROBINS-I) tool (<https://sites.google.com/site/riskofbiastool/>). This tool assesses each trial on seven domains of bias (Table 4) as well as an overall assessment of risk of bias. Almost all of the studies [7,8,14-16,18-22,24,25,27,32,35-38,41-43,45,46,49,53] had a moderate risk of bias, three studies had low risk of bias [13,28,54], and five studies had a serious risk of bias [10,11,17,33,34].

Table 4: Evaluation of included non-randomized controlled trials using Cochrane's ROBINS-I.

Study	Bias due to confounding	Bias in selection of participants into the study	Bias in classification of interventions	Bias due to departures from intended interventions	Bias due to missing data	Bias in measurement of outcomes	Bias in selection of the reported result	Overall
ADULT STUDIES								
Boettcher 2015 [7]	Mod	Mod	Low	Low	Low	Mod	Low	Mod
Davis 2015 [8]	Mod	Mod	Low	Low	NI	Mod	Mod	Mod
Kadlec 2015 [10]	Mod	Mod	Low	Low	Serious	Low	Low	Serious
Detering 2014 [11]	Mod	Mod	Low	Low	Serious	NI	Low	Serious
Pecanac 2014 [13]	Low	Low	Low	Low	Low	Low	Low	Low
Slort 2014a [14]	Mod	Low	Low	Low	Mod	Low	Low	Mod
Slort 2014b [15]	Mod	Low	Low	Low	Mod	Low	Low	Mod
Wheeler 2014 [16]	Mod	NI	Low	Low	Low	Mod	Low	Mod
Wilson 2014 [17]	NI	Serious	Low	Low	Mod	Low	Low	Serious
Abel 2013 [18]	Mod	Mod	Low	Low	Mod	Low	Low	Mod
Levi 2013 [19]	Mod	Mod	Low	Low	Mod	Mod	Mod	Mod
Millington-Sanders 2013 [20]	Mod	Mod	Low	Low	Low	NI	Low	Mod
Slort 2013 [21]	Mod	Low	Low	Low	Mod	Low	Low	Mod
Wilson 2013 [22]	Mod	Low	Low	Low	Low	Low	Low	Mod
Clayton 2012 [24]	Mod	Mod	Low	Low	Low	Low	Low	Mod
Colville 2012 [25]	Mod	Mod	Low	Low	Low	Mod	Mod	Mod
Resnick 2011 [27]	Low	Mod	Low	Low	NI	Low	Low	Mod
Hammes 2010 [28]	Low	Low	Low	Low	Low	Low	Low	Low
Newton 2009 [32]	Mod	Mod	Low	Low	Low	NI	Low	Mod
Hales 2008 [33]	Mod	Mod	Low	Low	Serious	Low	Low	Serious
Runkle 2008 [34]	Mod	Mod	Low	Low	Serious	NI	Low	Serious
Alexander 2006 [35]	Mod	Low	Low	Low	NI	Low	Mod	Mod
Lorin 2006 [36]	Mod	Low	Low	Low	Low	Low	Low	Mod
Zapka 2006a [37]	Mod	Mod	Low	Low	Low	Low	Low	Mod
Zapka 2006b [38]	Mod	Mod	Low	Low	Low	Low	Low	Mod
Wissow 2004 [41]	Mod	Low	Low	Low	Low	Low	Low	Mod
Ahrens 2003 [42]	Mod	Mod	Low	Low	Low	NI	Low	Mod
Bricker 2003 [43]	Mod	Mod	Low	Low	Low	NI	Low	Mod
Pauls 2001 [45]	Mod	Mod	Low	Low	Mod	Mod	Mod	Mod
Ratner 2001 [46]	Mod	Mod	Low	Low	Low	NI	Mod	Mod
Railey 1999 [49]	Mod	Low	Low	Low	Low	Low	Low	Mod
PEDIATRIC STUDIES								
Mitchell 2013 [53]	Mod	Low	Low	Low	Low	Low	Low	Mod
Walter 2013 [54]	Low	Low	Low	Low	Low	Low	Low	Low

Mod = moderate risk of bias; NI = no information

Outcomes

Initiating and Facilitating ACP or GoCD

Adult Studies

No clear distinction has been made between clinical tools that either introduce or facilitate both ACP and GoCDs and, as such, these two search criteria were combined.

The ACP provider tool most often encountered in the literature is Respecting Choices® or tools based on the Respecting Choices® program (e.g., patient-centred ACP, Honoring Choices Minnesota) (see Table 5). A key feature of this program is the use of trained facilitators for the ACP process. All studies addressing the Respecting Choices® program describe various patient outcomes. In general, exposure to a Respecting Choices® type of intervention, compared with controls, can result in: increased AD completion [2,7,13]; increased appointment of a surrogate [2]; more involvement in EOL decisions [2]; increased consistency between patient wishes and medical interventions undertaken at EOL [2,28]; increased patient and surrogate satisfaction with care received [2]; increased ACP knowledge [29,30,44]; fewer symptoms of anxiety and depression in family members of decedents [2]; decreased decisional conflict [40]; and increased consistency between wishes of patients and their surrogates [29,30,40,44]. Only one study described provider outcomes. This study reported that case managers trained and certified by Respecting Choices® demonstrated increased motivation, confidence, preparedness, and skill in facilitating ACP discussions at three months post-training compared with immediately after training. However, no p-values are reported [7].

Although there are different views on its relationship with GoCD, a commonly used provider tool is the Physician Orders for Life Sustaining Treatment (POLST) form. POLST is a standardized form containing medical orders that reflect a patient's treatment preferences. One recent systematic review of this tool that included 23 studies was identified [9]. It may be prepared by a non-physician facilitator and then reviewed and signed by a physician. Healthcare providers report that POLST expresses patient preferences reliably, guides care, improves communication, and helps in initiating EOL care discussions. POLST has challenges as well including the following difficulties: explaining the form, obtaining physician signatures, and transferring the form between settings, as well as issues regarding the time needed to complete the form [9]. Overall, it has been reported that there is high consistency between code status and treatment received by patients as well as between antibiotic use and wishes of patients. There is general consistency between artificial nutrition use and patient wishes. There are mixed results in terms of the consistency between the level of medical intervention requested and received by patients [9].

Three studies of the Availability, Current Issues and Anticipation (ACA) tool were identified [14,15,21]. ACA training is an eight-step program that takes approximately six hours to complete over a six-month time period. Briefly, it is an iterative process of role-playing and simulated patient interviews, followed by feedback and revision of learning goals. When tested in simulated and real palliative care patients, there were no significant differences between intervention and control groups on any of the outcomes measured (Table 5).

Two studies of the Making Your Wishes Known (MYWK) tools were identified [19,26]. MYWK is an interactive, online decision aid to help adults complete an AD. Providers use the decision aid to facilitate ACP with older patients. Green et al. [26] compared the effectiveness of the MYWK tool with a standard ACP planning package in medical students learning to facilitate ACP discussion with patients. Each student helped an adult aged ≥50 years old engage in ACP discussions. Compared with controls, students in the MYWK intervention group had significantly higher confidence in engaging in ACP and intervention

patient-participants were significantly more satisfied with their ACP planning method (Table 5).

There were also many one-off-type tools identified, some of which were named and others not. They all measured different and varied outcomes. In general, these various tools resulted in positive patient and provider outcomes (see Table 5 for more detail) including achieving preferred place of death when an ACP document is available [18].

Pediatric Studies

Only a few pediatric ACP (pACP) studies were identified [50-54] (Table 5). Lyon et al. [50,51] compared the Family-Centered Advance Care Planning (FACE) intervention with a control group that received current standard of care in teens with cancer and their surrogates. This RCT included 17 intervention and 13 control dyads. FACE consists of three sessions: a survey that assesses the values, beliefs, and experiences with EOL care in patients and their surrogates; a Respecting Choices® interview customized for adolescents; and completion of Five Wishes document (an AD document) customized for adolescents with a trained facilitator. Quality of communication was not different between groups. However, treatment preference congruence between control dyads was low for all scenarios tested whereas treatment preference congruence between intervention dyads was statistically significant for five of the six scenarios. Intervention adolescents thought they were significantly better informed regarding EOL decisions than did control adolescents ($p=0.007$). Moreover, intervention families all rated the three FACE sessions as worthwhile. Intervention adolescents had significantly lower depression scores at baseline and at the three-month follow-up compared with controls ($p=0.0268$). There were not significant differences in quality of life between intervention and control adolescents. More intervention than control adolescents completed ADs (100% vs. 0%).

A systematic review by Lotz et al. [52] uncovered only three pACP programs: FACE, Footprints, and Respecting Choices®. A review of these interventions revealed that many people are supportive of ADs for children although parents report discomfort of emergency personnel with ADs for children. Parents and adolescents find pACP interventions helpful for ensuring good care, providing time for decision making, facilitating communication among caregivers, and in providing peace of mind. They also found that fears about increasing distress in patients undertaking pACP are unfounded. However, some families do have difficulties thinking about a dismal future (Table 5).

A survey conducted by Mitchell et al. [53] found that 58% of pediatric intensive care units (PICUs) in the United Kingdom use a pACP document. All such documents were developed locally. Finally, Walter et al. [54] evaluated prognostic, goals-of-care conversations (PGOCC) in a review of 645 charts of children in the top decile for risk of mortality upon admission to the PICU in a children's hospital in Michigan. A documented PGOCC was found in 200 (31%) of charts. Patient characteristics significantly associated with a documented PGOCC were length of stay ($p<0.001$) and cancer diagnosis ($p<0.001$) (Table 5).

Table 5. Description and outcomes for included studies regarding introduction and facilitation of ACP or GoCD discussions.

Study	Tool Name	Study Type	Description	Outcomes
ADULT STUDIES				
RESPECTING CHOICES® OR BASED ON RESPECTING CHOICES®				
Boettcher 2014 [7]	Respecting Choices®	Repeated Measures (provider outcomes)	<ul style="list-style-type: none"> Insurance plan case managers (CMs) trained and certified by Respecting Choices® to develop skills needed to facilitate ACP with patients Conducted ACP discussions with frail patients with multiple co-morbidities via telephone 	<ul style="list-style-type: none"> Provider Outcomes <ul style="list-style-type: none"> 16 CMs trained Increased motivation, confidence, preparedness, and skill in facilitating ACP discussions at 3 months post-training compared to post-training (p values=NR) Patient Outcomes: <ul style="list-style-type: none"> N=56 patients 55 new or updated First Steps documents completed 4 Last Steps documents completed 50 telephone conversations included designated healthcare advocate
Detering 2014 [11]	Next Steps	Pre/Post Study	<ul style="list-style-type: none"> Evaluation of an ACP educational program for GPs and trainees Participants evaluated prior to and after ACP training Next Steps Program included: <ul style="list-style-type: none"> DVD Interactive patient e-simulation 2 hour workshop Training manual Next Steps ACP is a 4-step approach: <ul style="list-style-type: none"> Introduce ACP Explore concepts Introduce a solution Summary of conversation 	<ul style="list-style-type: none"> Provider Outcomes <ul style="list-style-type: none"> N=148 GPs Confidence to engage in ACP increased in 6 of 8 areas measured (all $p \leq 0.03$) Attitudes towards ACP were positive and not significantly different pre and post training except that after training there were significantly fewer doctors that considered ACP to be emotionally draining ($p=0.02$) Patient Outcomes <ul style="list-style-type: none"> None reported
Pecanac 2014 [13]	Respecting Choices®	Retrospective Chart Review	<ul style="list-style-type: none"> Prevalence and use of ADs in a racially and ethnically diverse community prior to and following implementation of Respecting Choices® Charts of all decedents in one hospital over 5 years 	<ul style="list-style-type: none"> Provider Outcomes <ul style="list-style-type: none"> None reported Patient Outcomes <ul style="list-style-type: none"> N=732 decedents After implementation prevalence of AD increased significantly for racial and ethnic minorities (25.8% to 38.4%, $p=0.011$) but not for whites (46.7% to 47.3%, $p=0.648$) Consistency between ADs and medical orders to restrict treatment was similarly high before and after RC implementation (74-96%, all $p=ns$) Consistency between ADs and orders to restrict treatment was similarly high before and after RC implementation for whites and racial and ethnic minorities (all $p=ns$)

Detering 2010 [2]	Respecting Choices®	RCT	<ul style="list-style-type: none"> • Comparison of usual care vs. usual care + facilitated ACP in inpatients ≥ 80 years old • Followed for 6 months or until death • Single centre study at one university hospital • ACP intervention was provided by a trained facilitator using Respecting Choices® 	<ul style="list-style-type: none"> • Provider Outcomes <ul style="list-style-type: none"> ○ None reported • Patient Outcomes <ul style="list-style-type: none"> ○ N=309 (N=154 intervention; N=155 control) ○ ACP provided to 125 patients (81%) ○ Advance care plan completed by 70 patients ○ Verbal wishes recorded by facilitator on ACP discussion card for another 38 patients ○ Appointment of a surrogate increased pre-intervention (18/154) vs. post-intervention (56/154) (p<0.001) ○ 25 of 29 (86%) intervention patients who died within 6 months had their wishes known and respected compared to 8 of 27 (30%) for the control group (p<0.001) ○ Intervention patients significantly more likely to be involved in EOL decision making compared to control patients (p=0.02). ○ Family members of intervention decedents were significantly more satisfied with quality of death compared to control family members (p=0.02) ○ Family members of intervention decedents had significantly fewer symptoms of depression (p=0.002) and anxiety (p=0.02) compared to control family members as measured by HADS ○ Upon hospital discharge, intervention patients (or family members if patient died) were significantly more satisfied (all p<0.001) than control patients with respect to: <ul style="list-style-type: none"> ▪ Hospital stay ▪ Information provided in hospital ▪ Being listened to in hospital ▪ Level of involvement in decisions made ▪ Level of family involvement in decisions made
Hammes 2010 [28]	Respecting Choices®	Retrospective Chart Review	<ul style="list-style-type: none"> • La Crosse Advance Directive Study (LADS) • Comparison of the success of Respecting Choices® over time [1995/96 (LADSI) vs. 2007/2008(LADSII)] in La Crosse County, Wisconsin • Conducted chart review of decedents from the two time periods • RC first implemented in 1993 • All healthcare organizations in La Crosse County use the RC program 	<ul style="list-style-type: none"> • Provider Outcomes <ul style="list-style-type: none"> ○ None reported • Patient Outcomes <ul style="list-style-type: none"> ○ N=540 decedents in 1995/96 (LADSI data) ○ N=400 decedents in 2007/08 (LADSII data) ○ Decedents with AD increased over time (85% vs. 90%; p=0.02) ○ Number of ADs in medical record at location of death increased over time (95.2% vs. 99.4%; p<0.001) ○ POA for healthcare increased over time (77% vs. 90%; p<0.001) ○ Number of living wills did not change over time (10% vs. 8%; p=0.41) ○ Dictated ACPs increased over time (13% vs. 33%; p<0.001). ○ Consistency with wishes (CPR and hospitalization) and medical interventions at EOL were high in LADSI (98%) and LADSII (99.5%) and not significantly different (p=0.14)

Schwartz 2002 [44]	Respecting Choices®	RCT	<ul style="list-style-type: none"> • Comparison of patients receiving Massachusetts Health Care Proxy form to complete (control) to patients who had ACP discussions with a trained nurse facilitator (intervention) • Participants were ≥ 65 years old with a chronic or life-threatening disease or ≥ 75 years old • Respecting Choices® program used for the intervention 	<ul style="list-style-type: none"> • Provider Outcomes <ul style="list-style-type: none"> ○ None reported • Patient Outcomes <ul style="list-style-type: none"> ○ N=31 intervention patients ○ N=30 control patients ○ Consistency between patients and health care agents regarding patient treatment goals at EOL were greater in the intervention group compared to the control group (76% vs. 55%; p= NR) ○ Intervention patients had greater increase in ACP knowledge compared to control patients (p=NR) ○ Intervention surrogates had a greater degree of comfort regarding their responsibility compared to control surrogates (p=NR)
Kirchhoff 2010/2012 [29,30]	Patient-Centered Advance Care Planning (PC-ACP)	RCT	<ul style="list-style-type: none"> • Comparison of usual care and PC-ACP with a trained facilitator with respect to surrogate understanding of future treatment goals of care for patients with life-limiting illnesses • Participants with CHF or ESRD and their surrogates • Six outpatient clinics in three cities in Wisconsin • PC-ACP, based on the Respecting Choices® program, was used for the intervention • PC-ACP is a 5-stage interview: <ul style="list-style-type: none"> ○ Assess patient understanding of current medical condition ○ Explore patient experiences that may have affected their goals for future treatment ○ Get patient and surrogate to understand the value of discussing future treatment options so that surrogate is properly prepared ○ Use a disease-specific Statement of Treatment Preference form to discuss real scenarios in order to aid the patient in verbalizing their own goals related to treatment outcomes ○ Summarize the discussion and articulate need for further discussions as situations and preferences change. • Explored 4 outcome scenarios as well as the amount of authority given to the surrogate <ul style="list-style-type: none"> ○ low chance of survival ○ severe permanent functional impairment ○ severe permanent cognitive impairment ○ sudden medical event requiring resuscitation • Patient treatment preferences were documented and compared with care received at EOL. • Study terminated early owing to expiration of funding; therefore underpowered 	<ul style="list-style-type: none"> • Provider Outcomes <ul style="list-style-type: none"> ○ None reported • Patient Outcomes <ul style="list-style-type: none"> ○ N=313 patient-surrogate dyads (160 intervention; 153 control) ○ N=6 trained research staff (nurses, social workers, chaplain) ○ In all 4 outcome scenarios as well as with amount of authority given to the surrogate, the intervention surrogates has significantly greater understanding of patient goals than the control surrogates (all p≤0.01) ○ Knowledge of ACP significantly greater in intervention patients and surrogates compared to controls (p=0.001) ○ In the situation of low chance of survival, 3 of 48 control patients who died and 1 of 62 intervention patients who died did not get what they wanted. ○ With respect to CPR, 6/48 control decedents and 1/62 intervention decedents did not get what they wanted (p=ns)

Song 2005 [40]	Patient Centered-Advance Care Planning (PC-ACP)	RCT	<ul style="list-style-type: none"> • Comparison of usual care and PC-ACP with a trained facilitator • Participants were patients undergoing cardiac surgery and their surrogates • Patients were from one cardiothoracic surgery clinic • PC-ACP, based on the Respecting Choices® program, was used for the intervention • Usual care patients were given an information package containing cards describing their right to have an AD • Explored 3 outcome scenarios 	<ul style="list-style-type: none"> • Provider Outcomes <ul style="list-style-type: none"> ◦ None reported • Patient Outcomes <ul style="list-style-type: none"> ◦ N=32 patient-surrogate dyads (16 intervention; 16 control) ◦ N=1 trained nurse facilitator ◦ Congruence in the 3 scenarios was significantly greater between the intervention dyads compared to the control dyads (p=0.002) ◦ Pre/post anxiety changes did not significantly differ between intervention and control patient and surrogates ◦ Decisional conflict was significantly lower in the intervention compared to the control group (p=0.02) ◦ ACP knowledge was not significantly different between the groups for their patients or surrogates
Wilson 2014 [17]	Honoring Choices Minnesota (HCM)	Non-comparative	<ul style="list-style-type: none"> • Describes the process used to implement HCM • Implementation done over 3 years starting in 2010 • Facilitators trained in the Respecting Choices® program • 8 large healthcare systems in one metropolitan area participated in the project 	<ul style="list-style-type: none"> • Provider Outcomes <ul style="list-style-type: none"> ◦ None reported • Patient Outcomes <ul style="list-style-type: none"> ◦ Five systems have provided inpatient data thus far ◦ 12.1% to 65.6% of inpatients have a health care directive in their electronic medical record ◦ Seven systems have provided information on all patients ◦ 15.1% to 31.7% of all patients have a health care directive in their electronic medical record
PHYSICIAN ORDERS FOR LIFE SUSTAINING TREATMENT (POLST)				
Hickman 2015 [9]	POLST	Systematic Review	<ul style="list-style-type: none"> • POLST form is a standardized form containing medical orders that reflect patient treatment preferences • Prepared by a non-physician facilitator • Physician reviews and signs • Contains 4 sections: <ul style="list-style-type: none"> ◦ A - Code status ◦ B - Preferred level of medical intervention ◦ C - Preferences regarding antibiotics ◦ D - Preferences regarding artificial nutrition • This systematic review has 23 included studies • Search period - Jan 1, 1990 to June 30, 2014 • Sample size of included studies ranges from 11 to 58,000 	<ul style="list-style-type: none"> • Provider Outcomes <ul style="list-style-type: none"> ◦ Providers report that POLST expresses patient preferences reliably, guides care, improves communication and helps in initiating EOL care discussions ◦ Providers in facilities with higher vs. lower POLST use more likely to report positive experiences ◦ Challenges of POLST include: <ul style="list-style-type: none"> ▪ Difficulty understanding and explaining the form ▪ Obtaining physician signatures ▪ Transferring the form across settings ▪ Family disagreements with content ▪ Inadequate provider education ▪ Time required to complete the POLST form • Patient Outcomes <ul style="list-style-type: none"> ◦ Section A - high rates of consistency with code status and treatment patients received ◦ Section B - mixed results with respect to consistency between POLST form wishes and treatment received ◦ Section C - high rates of consistency between antibiotic use and Section C POLST orders ◦ Section D - general consistency between artificial nutrition use and Section D POLST orders

AVAILABILITY, CURRENT ISSUES & ANTICIPATION (ACA)			
Stort 2014a [14]	ACA	Controlled Trial	<ul style="list-style-type: none"> • Comparison of third-year general practice trainees (GPT) who underwent ACA training (intervention) and those who did not (control) in a consultation with a simulated palliative care patient • Measured how the GPT communicated and what they discussed with the patient • Measurement by 3 trained raters • ACA training is a 8 step program that takes approximately 6 hours to complete over a 6-month period <ul style="list-style-type: none"> ○ Step 1 - GPT-simulated patient interview ○ Step 2 - Instructions on the ACA checklist ○ Step 3 - Feedback on interview in step 1 using the ACA checklist ○ Step 4 - Study the ACA checklist in small group setting ○ Step 5 - Devise learning goals based on previous steps ○ Step 6 - Take part in role-playing exercises ○ Step 7- Another GPT-simulated patient interview ○ Step 8 - Evaluation of 2nd interview and revision of learning goals
			<ul style="list-style-type: none"> • Provider Outcomes <ul style="list-style-type: none"> ○ None reported • Patient Outcomes <ul style="list-style-type: none"> ○ N=54 intervention ○ N=51 control ○ No significant differences between the groups with respect to the mean number of ACA issues (current or anticipated) discussed. ○ Significant differences between the groups with respect to only 3 types of affective utterances. No other significant differences with respect to quality of communication
Stort 2014b [15]	ACA	Controlled Trial	<ul style="list-style-type: none"> • Comparison of General Practitioners (GPs) who underwent ACA training (intervention) and those who did not (control) in consultations with palliative care patients • Outcome Measures completed by patients: <ul style="list-style-type: none"> ○ Palliative Care Outcome Scale (POS) ○ EORTC QLQ - Core 15 Palliative ○ Rest & Peace Scale (RPS) ○ Patient Satisfaction Questionnaire <ul style="list-style-type: none"> ▪ Interpersonal manner subscale ▪ Communication subscale ▪ Time spent with GP subscale ○ ACA Scale
			<ul style="list-style-type: none"> • Provider Outcomes <ul style="list-style-type: none"> ○ None reported • Patient Outcomes <ul style="list-style-type: none"> ○ N=62 GPs in intervention group ○ N=64 GPs in control group ○ No significant differences between the groups on any of the outcome scales completed
Stort 2013 [21]	ACA	Controlled Trial	<ul style="list-style-type: none"> • Comparison of General Practitioners (GPs) who underwent ACA training (intervention) and those who did not (control) in consultation with a simulated palliative care patient • Measured how the GPT communicated and what they discussed with the patient • Measurement by 4 trained raters
			<ul style="list-style-type: none"> • Provider Outcomes <ul style="list-style-type: none"> ○ N=62 GPs in intervention group ○ N=64 GPs in control group ○ No significant differences between the groups with respect to the mean number of ACA issues (current or anticipated) discussed. ○ No significant differences with respect to quality of communication • Patient Outcomes <ul style="list-style-type: none"> ○ None reported
MAKING YOUR WISHES KNOWN (MYWK)			

Levi 2013 [19]	Making Your Wishes Known (MYWK)	Qualitative Evaluation	<ul style="list-style-type: none"> • Evaluation of third-year medical students experiences with MYWK which is an interactive, online decision aid to help adults complete an advance directive • MYWK helps users through the ACP process by providing: <ul style="list-style-type: none"> ○ education ○ values clarification exercises ○ decision-making algorithm which will generate a personalized advance directive • Each student helped an adult (patient, friend or family member) engage in ACP using MYWK and then wrote an essay about the experience • Essays were evaluated iteratively by 3 investigators independently and then themes were identified 	<ul style="list-style-type: none"> • Outcomes <ul style="list-style-type: none"> ○ N=89 (64 students completed essays) ○ Four themes emerged: <ul style="list-style-type: none"> ○ (1) Student experiences with ACP <ul style="list-style-type: none"> ▪ Emotionally challenging ▪ Satisfaction with the exercise ▪ Differences between student expectations of the ACP conversations and the actual conversations ▪ Surprised by participants views of EOL care ○ (2) Participant experiences with ACP <ul style="list-style-type: none"> ▪ Generally student thought participants found the exercise to be valuable and comforting ▪ Some participants unprepared to address ACP resulting in evasive responses, sadness, fear, annoyance or anger ▪ Difficulty relating to parts of the exercise if the participant felt too young to address EOL issues ▪ Difficulty relating to ACP because of cultural practices ○ (3) Recommendations regarding ACP in practice <ul style="list-style-type: none"> ▪ Completion of an AD should be done with a loved one present to aid in participants ability to communicate what they want ▪ Importance of having a physician work with patients in completing ADs ▪ ACP very time consuming ○ (4) Feedback regarding the MYWK program <ul style="list-style-type: none"> ▪ User-friendly and clear ▪ Requires too high a health literacy to be used on its own ▪ Valuable resource
Green 2011 [26]	Making Your Wishes Known (MYWK)	RCT	<ul style="list-style-type: none"> • Comparison of effectiveness of a computer decision aid vs. a standard ACP planning packet in teaching a medical student to facilitate EOL discussions and help older patients complete an AD • Each student helped an adult, aged ≥50 years old (patient, friend or family member) engage in ACP discussions 	<ul style="list-style-type: none"> • Provider Outcomes <ul style="list-style-type: none"> ○ N=121 students ○ N=60 MYWK intervention group ○ N=61 standard ACP package control group ○ ACP Knowledge significantly increased in intervention group (p<0.01) ○ Student confidence in engaging in ACP increased significantly in both groups but more so in intervention group (p<0.01) • Patient Outcomes <ul style="list-style-type: none"> ○ Patient satisfaction with student significantly greater in intervention group (p<0.01) ○ Patient satisfaction with ACP planning method significantly greater in intervention group (p<0.01)
GENERAL COMMUNICATION/EDUCATION TOOLS				

Davis 2015 [8]	Conversation Project	Qualitative Evaluation	<ul style="list-style-type: none"> • Goal of Conversation Project is to ensure patients and their families have their EOL needs met • Project implemented differently on different wards 	<ul style="list-style-type: none"> • Provider Outcomes <ul style="list-style-type: none"> ○ Increase in staff confidence in introducing and facilitating EOL conversations with patients and families particularly among junior doctors • Increase in documented EOL care plans in patient notes • Patient Outcomes <ul style="list-style-type: none"> ○ None reported
Kadlec 2015 [10]	Practice Support Program (PSP) - EOL Care Module	Repeated Measures	<ul style="list-style-type: none"> • PSP is a peer-to-peer training program offered as part of CME credit in British Columbia • Includes a module on EOL care • Surveys administered to GPs at the beginning of training, end of training and 3-6 months after training 	<ul style="list-style-type: none"> • Provider Outcomes <ul style="list-style-type: none"> ○ N=873 GPs ○ Response Rates to surveys: <ul style="list-style-type: none"> ▪ Baseline - 69.6% ▪ End of Training - 55.6% ▪ 3-6 month follow up - 24.8% ○ During training period number of GPs who developed a registry for patients needing EOL care increased (7.9% to 65.9%, $p<0.0001$); there was a significant drop at the 3-6 month follow up (13.5%; $p=0.004$) ○ During training, development of an action plan for patients increased significantly ($p=NR$) and continued to rise after training completed ($p<0.0001$) ○ GP confidence with respect to 11 skills increased between baseline and end of training (all $p<0.0001$); further increases at 3-6 month follow up were not significant • Patient Outcomes <ul style="list-style-type: none"> ○ None reported
Wheeler 2014 [16]	Foundations in End of Life/Palliative Care	Pre/Post Study	<ul style="list-style-type: none"> • Module uses distance learning and practice-focused approach; 6 study days over a 6-month period of time. • Participants evaluated prior to and after completing module 	<ul style="list-style-type: none"> • Provider Outcomes <ul style="list-style-type: none"> ○ N=62 community nurses ○ Increased confidence in ACP to achieve preferred place of care and death • Patient Outcomes <ul style="list-style-type: none"> ○ None reported
Abel 2013 [18]	Planning Ahead	Retrospective Cohort	<ul style="list-style-type: none"> • Comparison of decedents with and without a completed ACP from a hospice over 2.5 years • Hospice uses a single unifying document called Planning Ahead for documenting ACP 	<ul style="list-style-type: none"> • Provider Outcomes <ul style="list-style-type: none"> ○ None reported • Patient Outcomes <ul style="list-style-type: none"> ○ N=969 decedents ○ Completed ACP = 56% ○ Did not complete ACP = 44% ○ Overall 75% of patients with ACP achieved preferred place of death

Millington-Sanders 2013 [20]	Coordinate My Care (CMC)	Non-comparative	<ul style="list-style-type: none"> To evaluate an electronic palliative care co-ordination system called Coordinate My Care to document EOL preferences and co-ordinate them with the healthcare professionals caring for a given patient 	<ul style="list-style-type: none"> Provider Outcomes <ul style="list-style-type: none"> None reported Patient Outcomes <ul style="list-style-type: none"> N=597 patients put on CMC N=138 decedents during study Preferred vs. Actual place of death (p=NR) <ul style="list-style-type: none"> Home - 41% vs. 29% Care Home - 16% vs. 14% Hospice - 11% vs. 11% Hospital - 5% vs. 33%
Au 2012 [23]	NA	Cluster-RCT	<ul style="list-style-type: none"> Comparison of a communication intervention using patient-specific feedback form vs. no patient feedback form to facilitate communication about EOL care in outpatients with COPD A one-page patient-specific feedback form was created based on patient's self-report responses regarding ACP and EOL care preferences The feedback form also included a sentence that providers could use to help initiate EOL conversations Feedback form was provided to patients and their providers in the intervention group only Clinicians in the intervention group received the form on the day of a regularly scheduled visit for a given patient and patients were surveyed 2 weeks following this visit 	<ul style="list-style-type: none"> Provider Outcomes <ul style="list-style-type: none"> 92 clinicians contributed 376 patients to the study N=182 control patients N=194 intervention patients Significant improvement in quality of communication in intervention group (p=0.03) Significantly more discussions regarding treatment preferences at last visit in intervention group (p<0.001) Patient Outcomes <ul style="list-style-type: none"> None reported
Clayton 2012 [24]	PREPARED	Pre/Post Study	<ul style="list-style-type: none"> Comparison of a time-effective communication training program to improve EOL communication with family caregivers for junior doctors working in hospitals Training took place over 4 weeks and included: <ul style="list-style-type: none"> 3 one-hour onsite teaching sessions Follow up phone call Written and audiovisual learning materials Participants evaluated one week prior to the intervention and two weeks following completion of the intervention 	<ul style="list-style-type: none"> Provider Outcomes <ul style="list-style-type: none"> N=22 junior doctors Communication Skills - all improved <ul style="list-style-type: none"> Clarity of information provided (p<0.001) Pacing of information (p=0.002) Empathy and Support (p=0.022) Skills related to PREPARED tool - 7 of 21 specific skills significantly improved following training: <ul style="list-style-type: none"> Use of plain language (p=0.039) Explores family's values and goals (p=0.039) Encourages questions (p=0.002) Explores family's understanding of palliative care (p=0.002) Explores family's understanding of patient's prognosis prior to no-CPR discussion (p=0.031) Explores family's fears about last days (p=0.031) CPR orders with respect to family goals for EOL care (p=0.006) Participant self-reported confidence in their communication skills regarding EOL discussions significantly improved for 14 of 15 items assessed. Patient Outcomes <ul style="list-style-type: none"> Not applicable

Colville 2012 [25]	NA	Descriptive Qualitative Study	<ul style="list-style-type: none"> • Exploration of nurses' experiences of facilitating ACP discussions following an ACP study day • Nurses interviewed 10-12 months following participation in ACP study day 	<ul style="list-style-type: none"> • Provider Outcomes <ul style="list-style-type: none"> ○ N=3 community nurses ○ N=3 acute care nurses ○ Three themes emerged: <ul style="list-style-type: none"> ○ (1) Bringing it all together <ul style="list-style-type: none"> ▪ Increased awareness of ACP ▪ Increased confidence to introduce the topic of ACP ○ (2) Talking about ACP - felling your way <ul style="list-style-type: none"> ▪ Increased awareness of need to assess whether or not a patient would want to participate in an ACP conversation ▪ Need to dedicate time to ACP ▪ Increased awareness of complexity of ACP especially if there was disagreement within a family ▪ Increases awareness of knowing when and how to initiate ACP discussions ○ (3) Planning future care <ul style="list-style-type: none"> ▪ Need to ensure patient wishes could be honoured • Patient Outcomes <ul style="list-style-type: none"> ○ Not applicable
Szmilowicz 2010 [31]	NA	RCT	<ul style="list-style-type: none"> • Comparison of a one day communication skills training workshop vs. no training on the ability of 2nd year internal medicine residents to perform EOL discussions • Participants evaluated before and after the intervention by questionnaire and by conversations with a standardized patient • Conversations evaluated by 2 blinded raters 	<ul style="list-style-type: none"> • Provider Outcomes <ul style="list-style-type: none"> ○ N=49 residents (23 intervention; 26 control) ○ Breaking Bad News - No significant differences in pre/post scores in either group ○ Direction of Total Care - No significant differences in pre/post scores in either group ○ Self-Assessed Confidence - only one difference - significantly higher preparation to break bad news in the intervention group • Patient Outcomes <ul style="list-style-type: none"> ○ None reported
Newton 2009 [32]	Preferred Priorities of Care (PPC)	Non-comparative Study	<ul style="list-style-type: none"> • Evaluate impact of the introduction of an ACP into community and inpatient locations using document called Preferred Priorities of Care • PPC documents patient and carer choice 	<ul style="list-style-type: none"> • Provider Outcomes <ul style="list-style-type: none"> ○ None reported • Patient Outcomes <ul style="list-style-type: none"> ○ N=211 PPCs initiated ○ N=182 decedents during study ○ Preferred vs. Actual place of death (p=NR) <ul style="list-style-type: none"> ▪ Home - 64% vs. 47% ▪ Care Home - 4% vs. 7% ▪ Hospice - 25% vs. 22% ▪ Hospital - 7% vs. 23%

Hales 2008 [33]	NA	Pre/Post Study	<ul style="list-style-type: none"> • Evaluation of a one-day EOL communication workshop using standardized families (SF) and standardized colleagues (SC) 	<ul style="list-style-type: none"> • Provider Outcomes <ul style="list-style-type: none"> ○ N=18 critical care practitioners who returned both pre- and post-workshop evaluations ○ Comfort Levels with EOL Topics - significant improvement post-workshop for all aspects measured (all $p < 0.05$) except for approaching cultural differences • Patient Outcomes <ul style="list-style-type: none"> ○ None reported
Runkle 2008 [34]	Four Habits Approach	Repeated Measures	<ul style="list-style-type: none"> • Evaluation of a communication workshop focused on ACP and related issues • Participants evaluated by survey prior to and immediately after the workshop and again 3 months after the workshop 	<ul style="list-style-type: none"> • Provider Outcomes <ul style="list-style-type: none"> ○ N=249 clinicians ○ N=185 clinicians who completed the pre/post surveys ○ N=103 clinicians who completed all three surveys ○ Knowledge <ul style="list-style-type: none"> ▪ significant increase between pre and post intervention surveys ($p = 0.016$) ▪ significant increase in between pre- and 3-months post intervention ($p = 0.04$) surveys ○ Confidence <ul style="list-style-type: none"> ▪ significant increase in confidence for all 15 communication topics ($p = 0.000$) - data not shown in paper ○ Confidence Regarding Advance Directives <ul style="list-style-type: none"> ▪ significant increase in confidence at 3 months survey that advance directive conversations would occur more regularly ($p \leq 0.05$) • Patient Outcomes <ul style="list-style-type: none"> ○ None reported
Alexander 2006 [35]	Program of Resident Education to Promote Awareness and Respect at the End of life (PREPARE)	Prospective Controlled Trial	<ul style="list-style-type: none"> • Evaluation of a 2-day communication course focused on delivering bad news and eliciting patient preferences regarding EOL care in internal medicine residents • Intervention consisted of lectures, discussions, and role-playing delivered in small groups • Evaluation by 2 blinded raters was based on standardized patient encounters prior to and after the intervention 	<ul style="list-style-type: none"> • Provider Outcomes <ul style="list-style-type: none"> ○ N=37 intervention group ○ N=19 control group ○ Delivering Bad News scores significantly higher in intervention group compared to controls ($p = 0.04$) ○ Patient Preferences for Life-Sustaining Care scores were not different between the groups • Patient Outcomes <ul style="list-style-type: none"> ○ None reported
Lorin 2006 [36]	NA	Prospective Comparison	<ul style="list-style-type: none"> • Evaluation of a teaching session about clinician-family communication in 4th year medical students • Session included <ul style="list-style-type: none"> ○ Lecture on a framework for communication ○ Discussion on how to use the framework ○ Practice in applying the framework with an actor posing as a family member of an ICU patient • Evaluation based on interaction with a standardized family member and scored by one blinded investigator 	<ul style="list-style-type: none"> • Provider Outcomes <ul style="list-style-type: none"> ○ N=106 students ○ Intervention scored significantly higher (all $p < 0.01$) for: <ul style="list-style-type: none"> ▪ gathering information ▪ imparting information ▪ setting goals and expectations • Patient Outcomes <ul style="list-style-type: none"> ○ None reported

Zapka 2006a	Healing Words: Communication with Advanced Heart Failure Patients at the End-of-life	Pre/Post Study	<ul style="list-style-type: none"> Evaluation of a 1-hour seminar designed to increase ACP communication skills of inpatient RNs of advanced heart failure patients Seminar included: <ul style="list-style-type: none"> 15 minute slide presentation 45 minute case study discussion Evaluation was based on self-report surveys completed at the start of each seminar and two-months following completion of the seminar 	<ul style="list-style-type: none"> Provider Outcomes <ul style="list-style-type: none"> N=57 RNs Preparedness to care for EOL patients significantly increased post-seminar (p<0.001) Ability to discuss EOL decisions with patients did not change Ability to discuss EOL decisions with family did not change Attitudes about EOL care (all measures) did not change Documentation about EOL discussions in medical record significantly improved following intervention (p=0.013) Patient Outcomes <ul style="list-style-type: none"> None reported
Zapka 2006b	Advanced Heart Failure: A Workshop on Clinical Guidelines and Healing Words	Pre/Post Study	<ul style="list-style-type: none"> Evaluation of a 4-hour workshop designed to improve care through communication and ACP of healthcare providers of advanced heart failure patients Evaluation was based on surveys completed at the start of each workshop and 5 weeks following completion of the workshop 	<ul style="list-style-type: none"> Provider Outcomes <ul style="list-style-type: none"> N=52 healthcare providers Ability to discuss EOL decisions with patients improved but not significantly so (p=0.05) Ability to discuss EOL decisions with families improved but not significantly so (p=0.05) Attitudes about EOL care (all measures) did not change Self-assessed Communication Skill significantly improved (p=0.009) Documentation about EOL discussions in medical record significantly improved following intervention (p<0.001) Patient Outcomes <ul style="list-style-type: none"> None reported
Pearlman 2005 [39]	Your Life, Your Choices	RCT	<ul style="list-style-type: none"> Comparison of an educational and motivational intervention vs. control to increase ACP use in outpatients ≥ 55 years of age with chronic health condition(s) Intervention <ul style="list-style-type: none"> ACP workbook (Your Life, Your Choices) Motivational counseling Reminder to providers to discuss ACP Control <ul style="list-style-type: none"> Advance directive booklet 	<ul style="list-style-type: none"> Provider Outcomes <ul style="list-style-type: none"> N=23 providers Patient Outcomes <ul style="list-style-type: none"> N=119 intervention N=129 control ACP discussions after index visit significantly greater in intervention vs. control groups (64% vs. 38%, p<0.001) Report of having a living will significantly greater in intervention vs. control groups (63% vs. 44%, p<0.01) Living wills filed in medical records significantly more in intervention vs. control group (48% vs 23%, p<0.001)
Wissow 2004 [41]	NA	Prospective, Quasi-experimental Design	<ul style="list-style-type: none"> Comparison of an provider and patient intervention vs. control to increase ACP use in outpatients ≥ 65 years old Patient Intervention <ul style="list-style-type: none"> Pre- and post-visit reminder letters about ADs Provided with "Planning Ahead" brochure Provider Intervention <ul style="list-style-type: none"> Presentations by chief of internal medicine "Desk Book" provided containing sample scripts for discussing ADs, FAQ responses etc. Checklist attached to patient charts Reminder stickers 	<ul style="list-style-type: none"> Provider Outcomes <ul style="list-style-type: none"> None reported Patient Outcomes <ul style="list-style-type: none"> N=2120 total N= 842 from 5 intervention centres N=1278 from control centre New AD made significantly more often in intervention vs. control groups (7.8% vs. 0.7%, p<0.001)

Railey 1999 [49]	NA	Pre/Post Study	<ul style="list-style-type: none"> Evaluation of an educational intervention to increase AD discussions in a family practice residency program Intervention includes lectures on various aspects of ADs 	<ul style="list-style-type: none"> Provider Outcomes <ul style="list-style-type: none"> None reported Patient Outcomes <ul style="list-style-type: none"> N=130 pre-intervention N=163 post-intervention AD discussion occurred more often post-intervention than pre-intervention (16.6% vs. 0%; p=NR)
OTHER				
Paladino 2014 [12] abstract	Serious Illness Conversation Guide	Cluster RCT	<ul style="list-style-type: none"> Comparison of computer-generated reminders (triggers) immediately prior to an outpatient visit vs. none for oncologist clinicians (MDs, NPs, PAs) to discuss ACP in patients previously identified as likely to die within the next year. Intervention oncologists undergo 2-1/2 hours training using the Serious Illness Conversation Guide. 	<ul style="list-style-type: none"> Interim data, only reported on Intervention Arm N=40 clinicians N=104 patients 62 completed ACP conversations 79% occurred after first trigger 92% occurred by the second trigger
Ahrens 2003 [42]	NA	Prospective Comparison	<ul style="list-style-type: none"> Comparison of a physician-CNS communication team vs. usual care in care of patients at high risk of death in ICU Physician-CNS team <ul style="list-style-type: none"> Physician provided family and patient with daily medical updates, provided medical advice with respect to treatment and care Gave daily goals Provided options for non-curative care Physician and nurse spoke as a team with patients/families whenever possible CNS provided information to families daily and clarified issues as they arose CNS discussed care plan and ensured that any issues were dealt with promptly 	<ul style="list-style-type: none"> Provider Outcomes <ul style="list-style-type: none"> None reported Patient Outcomes <ul style="list-style-type: none"> N=43 intervention N=108 control Mean hospital LOS significantly lower in intervention vs. control group (11.3 vs 16.4 days; p=0.03) Mean ICU LOS significantly lower in intervention vs. control group (6.1 vs 9.5 days; p=0.009) Hospital costs were also significantly lower in intervention vs. control group
Ratner 2001 [46]	Kitchen Table Discussion	Case Series	<ul style="list-style-type: none"> Evaluation of a an ACP intervention in which social workers discussed EOL issues during home visits to patients with life-limiting illness 	<ul style="list-style-type: none"> Provider Outcomes <ul style="list-style-type: none"> None reported Patient Outcomes <ul style="list-style-type: none"> N=84 83 (99%) patients accepted the offer of assistance with ACP 54(64%) expressed a preference for location of EOL care: <ul style="list-style-type: none"> Home - 85% Hospice - 6% Nursing Home - 9% Hospital - 0% Location of Death for the 58 decedents: <ul style="list-style-type: none"> Home - 70% Hospice - 5% Nursing Home - 18% Hospital - 7%

<p>Tierney 2001/Dexter 1998 [47,48]</p>	<p>Computer generated reminders</p>	<p>2x2 factorial RCT</p>	<ul style="list-style-type: none"> • Comparison of computer-generated reminders to discuss one or both types of ADs vs. no reminders to increase AD discussions and completion in outpatients 	<ul style="list-style-type: none"> • Provider Outcomes <ul style="list-style-type: none"> ○ None reported • Patient Outcomes <ul style="list-style-type: none"> ○ N=1009 ○ Patients in all 3 reminder groups had more AD discussions compared to control; OR(95%CI): <ul style="list-style-type: none"> ▪ Proxy Directive - OR=2.5(1.1-5.5) ▪ Instruction Directive - OR=4.4(2.1-9.4) ▪ Both - 7.7(3.4-18) ○ Patients whose physicians received both reminders completed more forms than those whose physicians received no reminders or only proxy directive reminders ○ Strongest predictor of patient satisfaction with a follow up visit was having discussed ADs previously (p=0.004)
<p>PEDIATRIC STUDIES</p>				
<p>Lyon 2014/2013 [50,51]</p>	<p>FACE-TC</p>	<p>RCT</p>	<ul style="list-style-type: none"> • Comparison of FACE vs. standard of care control group • FACE consists of three sessions <ul style="list-style-type: none"> ○ Session 1 - Lyon Family-Centered ACP Survey-Adolescent and Surrogate Version <ul style="list-style-type: none"> ▪ Assesses values, beliefs, experiences with illness and EOL care ○ Session 2 - Respecting Choices® Interview for dyads <ul style="list-style-type: none"> ▪ Customized to adolescents with cancer ○ Session 3 - Five Wishes completed by adolescents with assistance of a trained facilitator <ul style="list-style-type: none"> ▪ Customized to adolescents, aged 14-21, with cancer ▪ An AD document • Intervention dyads were evaluated at the three sessions as well as at baseline and 3-month follow up • Control dyads were assessed at the same time points as intervention dyads 	<ul style="list-style-type: none"> • Provider Outcomes <ul style="list-style-type: none"> ○ None reported • Patient Outcomes <ul style="list-style-type: none"> ○ N=30 dyads (17 intervention and 13 control) ○ Quality of communication not different between groups ○ Treatment preference congruence between control dyads was low for all 6 scenarios presented ○ Treatment preference congruence between intervention dyads was statistically significant in 5 of the 6 scenarios ○ Intervention adolescents thought they were significantly better informed regarding EOL decisions than their control counterparts (p=0.007) ○ Intervention families all rated the 3 FACE sessions as worthwhile ○ Anxiety decreased significantly in adolescents in both groups ○ Intervention adolescents had significantly lower depression scores at baseline and at 3-month follow up compared to control adolescents (p=0.0268) ○ No significant differences in QOL between intervention and control adolescents ○ Spirituality of intervention adolescents significantly higher than controls at baseline and at 3 month follow up ○ More intervention than control adolescents completed advanced directives (100% vs. 0%) <ul style="list-style-type: none"> ▪ AD easily found in medical record at 3 month follow up

Lotz 2013 [52]	FACE, Footprints, Respecting Choices	Systematic Review	<ul style="list-style-type: none"> • Systematic review of literature regarding pediatric advance care planning (pACP) • This systematic review has 13 included studies <ul style="list-style-type: none"> ○ 8 quantitative ○ 5 qualitative • Search period - Jan 1, 1991 to January 20, 2012 • Sample size of included studies ranges from 12 to 214 • Identified only 3 pACP programs <ul style="list-style-type: none"> ○ FACE ○ Footprints ○ Respecting Choices 	<ul style="list-style-type: none"> • Overall: <ul style="list-style-type: none"> ○ Patients, surrogates, school nurses, physicians and health institutions are supportive of ADs for children ○ Parents and adolescents find pACP intervention helpful for ensuring good care, providing time for decision making, facilitating communication among caregivers and in providing peace of mind ○ Fears about increasing distress in patients undertaking pACP are unfounded ○ Parents report discomfort of emergency personnel with ADs for children ○ Some families have difficulties thinking about a dismal future
Mitchell 2013 [53]	NA	Survey	<ul style="list-style-type: none"> • Survey of lead clinicians from PICUs in the UK regarding pACP documents that are currently in use 	<ul style="list-style-type: none"> • N=28 PICUs contacted • N=24 responses received (86%) • 14 of 24 (58%) PICUs use an ACP document • All pACP documents were developed locally
Walter 2013 [54]	PGOCC	Chart Review	<ul style="list-style-type: none"> • Chart review of patients in the top decile for risk of mortality on admission to the PICU, from July 2004 to July 2010 at one children's hospital in Michigan 	<ul style="list-style-type: none"> • N=645 admissions • 200 (31%) had a documented PGOCC • 47 patients died during hospital stay • Patient characteristics significantly associated with PGOCC documented were: <ul style="list-style-type: none"> ○ Length of stay (p<0.001) ○ Cancer diagnosis (p<0.001)

ACP=advance care planning; AD=advance directive; CHF=congestive heart failure; CI=confidence interval; CME=continuing medical education; CNS=clinical nurse specialist; COPD=chronic obstructive pulmonary disease; CPR=cardiopulmonary resuscitation; EOL=end of life; ESRD=end-stage renal disease; FACE-TC=Family-Centered Advance Care Planning for Teens with Cancer; FAQ=frequently asked questions; GoCD=Goals of Care discussions; GP=general practitioner; HADS=Hospital Anxiety & Depression Scale; ICU=intensive care unit; LOS=length of stay; MD=medical doctor; NA=not applicable; NR=not reported; NP=nurse practitioner; ns=non-significant; OR=odds ratio; PA=physician assistant; PGOCC=prognostic, goals-of-care conversation; PICU=pediatric intensive care unit; POA=power of attorney; POLST=Physician Orders for Life Sustaining Treatment; PREPARE=Program of resident education to promote awareness and respect at the end of life; RC= Respecting Choices®; RCT=randomized controlled trial; RN=registered nurses; UK=United Kingdom

Documenting ACP or GoCD

Adult Studies

Evidence regarding the documentation of ACP or GoCD is sparse. Overall, storage of ACP documents is varied and inconsistent and the documents can be quite difficult to find even when they exist (Table 6). Wilson et al. [22] conducted a chart review to identify the location of ACP in the electronic health record (EHR) of patients at least 65 years old who were known to have an ACP document in their EHR. Most ACP, POLST, and ADs were not scanned into the EHR. Of those that were, they could be scanned, scanned and in progress notes, scanned and in the problem list, or all three. Patients had a mean of four scanned documents per year but the maximum was 231. Therefore, it was often extremely difficult to locate the ACP documents among them.

Colville et al. [25], in a qualitative evaluation, demonstrate the need to document ACP plans such that all providers of care for a given patient have access to them. Resnick et al. [27] surveyed a sample of home, health, and hospice agencies in the USA and found that AD storage varied. Most ADs were stored with the patient's record at the agency (94.4%), many were stored at the patient's residence (48.8%), and a few were stored in a special AD file at the agency (3.3%).

Bricker et al. [43] describe the development of an AD documentation process within an electronic medical record (EMR). They cite three options for creating an electronic AD: scanning the existing AD into the EMR; dictating an AD note using the existing telephone transcription service; and typing the AD note directly into the EMR. In all cases, the AD note was then highlighted within the list of EMR documents for ease of access. Moreover, single-page AD forms were developed for ease of completion and ease of scanning into the EMR. All personnel, from healthcare providers to transcriptionists, were made aware of this new system. The result was an increase in the number of completed electronic AD notes. A further benefit was that the patient preferences were accessible throughout the healthcare system.

Finally, Pauls et al. [45] describe a model for transferring ADs from a long-term care (LTC) facility to an emergency department (ED). The model consists of three parts: the form, completing the form, and using the form. The form itself is only one or two pages employing simple language and providing a choice of three or four levels of care from which to choose. In terms of form completion, LTC residents and their families were given education sessions regarding ACP and ADs as soon as they entered LTC. The forms are reviewed annually or when there have been changes in a patient's health. The completion of the forms involves various healthcare providers and they are remunerated. With respect to using the forms, they are kept in an accessible and consistent location and are printed on coloured paper for ease of transferability to the ED via paramedics.

Pediatric Studies

No pediatric studies regarding the documentation of ACP or GoCD were identified.

Ongoing, Unpublished, or Incomplete Studies

None.

Table 6. Description and outcomes for included studies for documentation of ACP or GoCDs.

Study	Tool Name	Study Type	Description	Outcomes
ADULT STUDIES				
Wilson 2013 [22]	EpicCare EHR	Chart Review	<ul style="list-style-type: none"> To identify location of ACP documents in EpicCare EHR in patients ≥65 who had at least one ACP document in their EHR. 	<ul style="list-style-type: none"> N=30,566 Location of ACP documents: <ul style="list-style-type: none"> No scanned document - 66.5% Scanned document - 33.5% <ul style="list-style-type: none"> Scanned document & Progress Notes - 6.2% Scanned document only - 4.5% Scanned document & Problem List - 1.2% All Three Locations - 21.6% Location of POLST documents: <ul style="list-style-type: none"> No scanned document - 95.8% Scanned document - 4.2% <ul style="list-style-type: none"> Scanned document & Progress Notes - 1.8% Scanned document only - 1.1% Scanned document & Problem List - 0.1% All Three Locations - 1.2% Location of AD/Living Wills: <ul style="list-style-type: none"> No scanned document - 65.2% Scanned document - 34.8% <ul style="list-style-type: none"> Scanned document & Progress Notes - 4.7% Scanned document only - 6.8% Scanned document & Problem List - 1.9% All Three Locations - 21.3% Patient had a mean of 4 scanned documents/year but the maximum was 231. Therefore difficult to find ACP document among them.
Colville 2012 [25]	NA	Descriptive Qualitative Study	<ul style="list-style-type: none"> Exploration of nurses' experiences of facilitating ACP discussions following an ACP study day Nurses interviewed 10-12 months following participation in ACP study day 	<ul style="list-style-type: none"> Provider Outcomes <ul style="list-style-type: none"> N=3 community nurses N=3 acute care nurses Three themes emerged - see Table 2 Theme 3 - Planning future care <ul style="list-style-type: none"> Need to document the plans so that they are accessible to all those caring for the patient
Resnick 2011 [27]	NA	Survey	<ul style="list-style-type: none"> Survey of a sample of home, health and hospice agencies in the USA 	<ul style="list-style-type: none"> Advance Directive Storage: <ul style="list-style-type: none"> With patient's record at agency - 94.4% At patient's residence - 48.8% In a special AD file at agency - 3.3%

Bricker 2003 [43]	NA	Descriptive	<ul style="list-style-type: none"> • Development of an AD documentation process within one healthcare system • Specifically developed an electronic AD note within the EMR • Developed short instructional video to increase patient understanding of the importance of ADs 	<ul style="list-style-type: none"> • 3 options for creating electronic AD <ul style="list-style-type: none"> ◦ Scan the existing AD document into the EMR ◦ Dictate AD note using existing telephone transcription service ◦ Type AD note directly into EMR • The AD note was then highlighted within the list of EMR documents for easy access • Single page forms developed for ease of completion of AD and for ease of scanning into EMR • Everyone in the system from healthcare providers to transcriptionists had to be aware of the new system • Number of completed electronic AD notes increased and continues to increase • Informal polling of healthcare providers indicates that they like that patient preferences are available throughout this healthcare system
Pauls 2001 [45]	NA	Descriptive	<ul style="list-style-type: none"> • Description of a model to transfer an AD from LTC to EDs 	<ul style="list-style-type: none"> • Model - 3 parts • (1) The Form <ul style="list-style-type: none"> ◦ 1 or 2 pages ◦ Simple language ◦ 3 or 4 levels of care to choose from ◦ Physician signature • (2) Completing the Form <ul style="list-style-type: none"> ◦ Education sessions for LTC residents/families about AD, ACP as soon as residents enters LTC ◦ Review annually or with change in health ◦ Involve various healthcare providers and remunerate them • (3) Using the Form <ul style="list-style-type: none"> ◦ Keep in accessible and consistent location and have on coloured paper for ease of transferability to ED via paramedics ◦ Obtain endorsement of regulatory authorities ◦ Hold providers accountable for following form ◦ Direct communication between healthcare providers ◦ Educate providers about AD and ACP

ACP=advance care plan; AD=advance directive; ED=emergency department; EHR=electronic health record; EMR=electronic medical record; EOL=end-of-life; LTC=long-term care; POLST=Physician Orders for Life Sustaining Treatment

DISCUSSION

Recently, considerable attention has been given to the important role for ACP conversations and GoCD in decision making for patients not only in the setting of serious illness, but also when there is no illness. Currently, no consensus exists as to the tools or processes clinicians should use to inform or guide ACP and GoCD. The purpose of this evidence summary was to identify existing tools that could be used for each of these clinical encounters. The specific questions that shaped this review were intended to reflect the elements clinicians find particularly challenging, i.e., introducing, facilitating, and documenting both ACP and GoCD. Although a number of studies reported positive findings, there is a lack of consistent patient outcomes evidence to support any one clinical tool for use in either ACP or GoCD. However, despite this, the evidence points to important elements for clinicians to consider when reflecting on their practice around ACP and GoCD. Also, certain evidence emerged that is important for healthcare leaders and system planners to consider. Of note, no clear distinction has been made between clinical tools that either introduce or facilitate both ACP and GoCDs and, as such, these two search criteria were combined.

There are common challenges providers encounter in clinical practice relating to ACP and GoCD. There continues to be a lack of widespread agreement on the definitions of ACP and GoCD, their critical elements, and desired outcomes. For example, in some studies and in practice, ACP has been equated with determining a person's resuscitation status, whereas others define it differently. This is problematic on several levels. However, for the purpose of this review, the lack of standard definitions prevents a unified approach to studying ACP and GoCD and contributes to great difficulty interpreting and comparing the findings among different studies. Improving a shared understanding of these concepts as described in this review is an essential step to establishing evidence for best practice. Similarly, consensus on outcomes are needed. The ideal ACP outcomes may include adequate understanding of the person's health status by the patient and their SDM, and the SDM understanding the patient's values, beliefs, and wishes as they relate to the patient's healthcare. The ideal GoCD outcome would be that current healthcare decisions are informed by the person's goals and values. This can occur at any point along the illness journey, but will always occur in relation to current, not future, healthcare decisions. Addressing these discrepancies will be beneficial for clinicians, for the development of tools and to guide evidence-informed best practices.

A second challenge in attempting to identify tools for clinicians is clarifying what might be considered appropriate tools for the contexts of introducing and facilitating these conversations. Additionally, different tools may be more or less effective for clinicians with varying expertise and competency in advanced communication skills, EOL communication skills, and values-based conversations. Finally, development and evaluation of tools must take into account the relationship of ACP and GoCD with regional laws on capacity, consent, and substituted decision making. It is important to note that tools structured for use by patients or caregivers without immediate clinical support were excluded from this review.

Finally, synthesizing evidence for ACP and GoCD is challenging owing to the nature of these two clinical encounters as each has inherent limitations to standardization. ACP is considered to be a process over time, which can lead to a lack of clarity and inconsistent practices around what could or what should be documented for any given clinical encounter. For GoCDs, there are different understandings of the expected outcomes or products of the clinical encounter and one standard approach has yet to be proposed or studied.

The majority of studies that met inclusion criteria address ACP-related processes (rather than GoCD), such as the occurrence of any kind of EOL conversation and documentation. Differences in the interpretations of the essential components of ACP are evident, with a key difference being the perceived importance of addressing specific

treatments in the conversations. However, it is worth pointing out that the tool with the largest evidence base is Respecting Choices®, which moves away from preferences for specific treatments and shifts toward a greater emphasis on patient values. Although this shift makes the desired outcome of the clinical interaction more challenging to capture, the evidence suggests values-based information is more likely to help future SDMs than treatment-based or treatment-focused ACP conversations. Considering these emerging themes from the evidence suggests that tool development should focus on enabling healthcare providers to facilitate values-based discussions. Future studies with corresponding values-based outcome measures are needed to evaluate the impact on patient care.

Irrespective of how ACP effectiveness might be defined, the evidence suggests it is critical to think beyond singular ACP elements in order to meaningfully impact patient care. The evidence related to the Respecting Choices® model outlines the high likelihood that a comprehensive, systematic approach to ACP is necessary. Ideal patient outcomes are unlikely to be achieved in the absence of broad systemic commitments to integrate and deliver ACP as part of routine care. A comprehensive approach to ACP includes community engagement, professional education, development of standard practices, monitoring of these practices through Quality Improvement initiatives, supporting policies and practices, and a technology infrastructures. This approach must be applied across public health and healthcare sectors to support the exchange of clinical information and will involve system-level coordination and planning. Addressing only one, or a few, of these elements creates the risks of leaving critical gaps that could prevent positive impacts on quality patient care.

The development of materials, clinical processes, and professional development experiences that improve communication skills, designed to enable clinicians to facilitate a discussion of a person's values, must be embedded in a system-wide approach to ACP. Evidence from studies addressing the ACA tool serve as important examples of this [14,15,21]. The associated education components of the intervention (i.e., simulation and direct feedback) are known to be highly effective from the perspectives of educational design and adult learning theory. However, high-quality education, although essential, on its own is unlikely to improve care or the patient experience in the absence of supporting systemic changes.

Important findings for the pediatric population mirror many of the early reports that address ACP in adults. The evidence outlines that, in general, children and their parents are supportive of ACP and find these discussions helpful to ensure good care, to facilitate communication among caregivers, and to provide peace of mind. Concerns that ACP discussions will cause distress in children and parents are not supported by the evidence. However, parents are aware of discomfort among clinicians attempting to navigate ACP discussions. This is an important area for further exploration and discovery.

Very few studies specifically address GoCDs and in large part this is likely due to GoCDs having been added to the healthcare lexicon relatively recently. There is a resultant lack of patient outcome evidence and many problematic elements in the research findings. These include a lack of widespread agreement on the expected outcomes, general approach, and components of GoCD. Detailed information regarding the specific clinical interaction was notably absent from studies involving the GoCD. Exploring the elements of GoCD that could be amenable to standardization would uncover important clinician tool-related information.

One specific element of the GoCD on which practices differ among clinicians is the perceived relationship with decision making. This ranges from considering GoCD to be separate and distinct from decision-making discussions to considering the two to be one and the same. These differing perspectives may parallel differences in how the POLST is viewed in relation to the GoCD. Some clinicians would likely view the POLST as a tool for use during the GoCD whereas others would not. For the purpose of this evidence review, we include POLST

studies with the caveat that this not be considered endorsement for its use as a GoCD or ACP tool. We have chosen to include the POLST to highlight this challenge and enable further discussion.

It should be highlighted that the Ontario legal context should preclude the widespread use of tools like the POLST for ACP conversations. Regional variation exists with regard to the completion of orders sets in advance of receiving healthcare. Practitioners should be familiar with their regional laws surrounding consent, capacity, and healthcare decision making. In Ontario, direction and decision making for a person's current care must come from a capable person (either the patient or their SDM if the patient is not capable), not a previously completed order set. In cases where the patient has been found incapable for a current decision, the SDM will rely on applicable previously expressed wishes or the person's values. This underscores the importance of ACP conversations as preparation of the SDM for many eventualities of future decision making.

The involvement of interprofessional healthcare providers was identified as an important element of the ACP process in a number of positive studies. The shift toward emphasizing patient values in the ACP context has expanded the facilitation of such discussions to include non-physician providers. The Respecting Choices® model demonstrates how the training of interested and willing clinicians, regardless of profession, may be a critical strategy for impacting patient outcomes. An example for GoCDs is the role of clinical nurse specialists and the communication skills they bring to the patient experience. Implementation of ACP as an interprofessional practice is an important consideration in addressing the concern of many physicians about not having adequate time for these discussions.

CONCLUSIONS

- Outcome evidence for ACP suggests the greatest impact is likely to be made by a system-wide approach to integrating ACP into practice, one that maximizes clinical skills of all interprofessional team members.
- What is likely to be of greatest value for the GoCD context is to achieve widespread agreement on the specific outcomes that should be expected?
- The most important patient-related outcome of any future planning or current care decision-making process is a patient receives the care that is wished for or desired.
- Inconsistencies in definitions and desired outcomes for both ACP and GoCD need to be addressed to enable better understanding of effective healthcare provider tools.

INTERNAL REVIEW

The evidence summary was reviewed by the Director of the PEBC. The Working Group is responsible for ensuring the necessary changes are made.

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ARCHIVED

Appendix 1: Members of the Working Group and their COI declaration (see the [PEBC Conflict of Interest \[COI\] Policy](#)).

Table 1. Members of the Advanced Care Planning/Goals of Care Working Group

Name	Affiliation	Declarations of interest
Jeff Myers Working Group Chair	Head, Palliative Care Consult Team, Sunnybrook Health Sciences Centre; Dept of Family & Community Medicine, University of Toronto	Declared they had no conflicts of interest.
Danusia Gzik	Primary Care Lead, Simcoe Muskoka Regional Cancer Program, Cancer Care Ontario	Declared they had no conflicts of interest.
Ingrid Harle	Postgraduate Program Director, Palliative Medicine Assistant Professor, Depts of Medicine and Oncology Queen's University Kingston, Ontario	Is a member of the ACP committee at Kingston General Hospital.
Deb Harrold	North Simcoe Muskoka Regional Palliative Care Lead	Within the past 5 years, spoke on local radio to encourage ACP in general.
Nadia Incardona	Hospitalist & Emergency Physician, Michael Garron Hospital, Toronto East Health Network; Dept of Family & Community Medicine, University of Toronto	Within the past 5 years: <ul style="list-style-type: none"> received a research and education grant at Toronto East General Hospital to study healthcare provider experiences with ACP in acute care. was the PI on a study about barriers to ACP in primary care. was the ACP Physician Lead for East Toronto HealthLink that received \$5000 or more from the Ontario Ministry of Health to develop ACP resources and online e- learning modules for healthcare providers and received a stipend for this work.
Tara Walton	Policy Research Analyst Palliative Care Program Cancer Care Ontario	Declared they had no conflicts of interest.
Roxanne Cosby	Health Research Methodologist Program in Evidence-Based Care McMaster University Hamilton, ON	Declared they had no conflicts of interest.

Appendix 2: Literature Search Strategy - Clinical Practice Guidelines

MEDLINE

1. advance care planning.mp. or Advance Care Planning/
2. acp.mp.
3. goals of care.mp.
4. goc.mp.
5. advance directives.mp. or Advance Directives/
6. palliative care.mp. or Palliative Care/
7. terminal care.mp. or Terminal Care/
8. end-of-life care.mp.
9. patient care planning.mp. or Patient Care Planning/
10. critical illness.mp. or Critical Illness/
11. decision making.mp. or Decision Making/
12. or/1-11
13. physician-patient communication.mp.
14. Communication/ or communication.mp.
15. interpersonal relations.mp. or Interpersonal Relations/
16. nurse-patient relations.mp. or Nurse-Patient Relations/
17. physician-patient relations.mp. or Physician-Patient Relations/
18. or/13-17
19. 12 and 18
20. (guideline or practice guideline).pt.
21. exp practice guidelines as topic/ or practice guidelines as topic.mp.
22. consensus development conference.mp. or exp consensus development conference/
23. consensus.mp. or exp consensus/
24. (guideline: or recommend: or consensus or standards).ti.
25. or/20-24
26. 19 and 25
27. (comment or letter or editorial or note or erratum or short survey or news or newspaper article or case report or historical article).pt.
28. 26 not 27
29. limit 28 to english language
30. limit 29 to yr="2010 - 2015"

EMBASE

1. critically ill patient.mp. or critically ill patient/
2. life sustaining treatment.mp. or life sustaining treatment/
3. palliative therapy.mp. or palliative therapy/
4. patient care planning.mp. or patient care planning/
5. terminal care.mp. or terminal care/
6. treatment planning.mp. or treatment planning/
7. patient care.mp. or patient care/
8. health care planning.mp. or health care planning/
9. living will.mp. or living will/
10. medical decision making.mp. or medical decision making/
11. clinical decision making.mp. or clinical decision making/
12. patient decision making.mp. or patient decision making/
13. advance care planning.mp.
14. acp.mp.
15. goals of care.mp.
16. goc.mp.
17. advance directives.mp.
18. or/1-17
19. interpersonal communication.mp. or interpersonal communication/
20. decision support system.mp. or decision support system/
21. communication skill.mp. or communication skill/
22. doctor-patient relations.mp. or doctor patient relation/
23. nurse-patient relation.mp. or nurse patient relationship/
24. or/19-23
25. 18 and 24
26. practice guideline.mp. or exp practice guideline/
27. (guideline: or recommend: or consensus: or standard).ti.
28. or/26-27
29. 25 and 28
30. (comment or letter or editorial or note or erratum or short survey or news or newspaper article or case report or historical article).pt.
31. 29 not 30
32. limit 31 to english language
33. limit 32 to yr="2010 - 2015"

Appendix 3: Literature Search Strategy - Systematic Reviews

MEDLINE

1. advance care planning.mp. or Advance Care Planning/
2. acp.mp.
3. goals of care.mp.
4. goc.mp.
5. advance directives.mp. or Advance Directives/
6. palliative care.mp. or Palliative Care/
7. terminal care.mp. or Terminal Care/
8. end-of-life care.mp.
9. patient care planning.mp. or Patient Care Planning/
10. critical illness.mp. or Critical Illness/
11. decision making.mp. or Decision Making/
12. or/1-11
13. physician-patient communication.mp.
14. Communication/ or communication.mp.
15. interpersonal relations.mp. or Interpersonal Relations/
16. nurse-patient relations.mp. or Nurse-Patient Relations/
17. physician-patient relations.mp. or Physician-Patient Relations/
18. or/13-17
19. 12 and 18
20. exp meta-analysis as topic/
21. meta-analysis.pt.
22. (systematic adj (review: or overview:)).mp.
23. (meta-analy: or metaanaly:).mp.
24. (pooled analy: or statistical pooling or mathematical pooling or statistical summar: or mathematical summar: or quantitative synthes?s or quantitative overview:).mp.
25. (exp review literature as topic/ or review.pt. or exp review/) and systematic.tw.
26. (cochrane or embase or psychlit or psyclit or psychinfo or psycinfo or cinahl or cinhal or science citation index or scisearch or bids or sigle or cancerlit or pubmed or pub-med or medline or medline).ab.
27. (reference list: or bibliograph: or hand-search: or handsearch: or relevant journal: or manual search:).ab.
28. or/20-27
29. (selection criteria or data extract: or quality assess: or jadam scale or methodologic: quality).ab.
30. (stud: adj1 select:).ab.
31. (29 or 30) and review.pt.
32. 28 or 31
33. 19 and 32
34. limit 33 to english language
35. limit 34 to yr="2010 - 2015"

EMBASE

1. critically ill patient.mp. or critically ill patient/
2. life sustaining treatment.mp. or life sustaining treatment/
3. palliative therapy.mp. or palliative therapy/
4. patient care planning.mp. or patient care planning/
5. terminal care.mp. or terminal care/
6. treatment planning.mp. or treatment planning/
7. patient care.mp. or patient care/
8. health care planning.mp. or health care planning/
9. living will.mp. or living will/
10. medical decision making.mp. or medical decision making/
11. clinical decision making.mp. or clinical decision making/
12. patient decision making.mp. or patient decision making/
13. advance care planning.mp.
14. acp.mp.
15. goals of care.mp.
16. goc.mp.
17. advance directives.mp.
18. or/1-17
19. interpersonal communication.mp. or interpersonal communication/
20. decision support system.mp. or decision support system/
21. communication skill.mp. or communication skill/
22. doctor-patient relations.mp. or doctor patient relation/
23. nurse-patient relation.mp. or nurse patient relationship/
24. or/19-23
25. 18 and 24
26. exp meta-analysis/ or exp "systematic review"/
27. (meta analy\$ or metaanaly\$).tw.
28. (systematic review\$ or pooled analy\$ or statistical pooling or mathematical pooling or statistical summar\$ or mathematical summar\$ or quantitative synthes\$s or quantitative overview\$).tw.
29. (systematic adj (review\$ or overview\$)).tw.
30. exp "Review"/ or review.pt.
31. (systematic or selection criteria or data extraction or quality assessment or jadad scale or methodological quality).ab.
32. (study adj selection).ab.
33. 30 and (31 or 32)
34. or/26-29,33
35. (cochrane or embase or psychlit or psyclit or psychinfo or psycinfo or cinhal or cinahl or science citation index or scisearch or bids or sigle or cancerlit).ab.
36. (reference list\$ or bibliograph\$ or hand-search\$ or relevant journals or manual search\$).ab.
37. 34 or 35 or 36
38. (editorial or note or letter or erratum or short survey).pt. or abstract report/ or letter/ or case study/
39. 37 not 38
40. 25 and 39
41. limit 40 to english language
42. limit 41 to yr="2010 - 2015"

Appendix 4: Literature Search Strategy - Primary Literature

MEDLINE

1. advance care planning.mp. or Advance Care Planning/
2. acp.mp.
3. goals of care.mp.
4. goc.mp.
5. advance directives.mp. or Advance Directives/
6. palliative care.mp. or Palliative Care/
7. terminal care.mp. or Terminal Care/
8. end-of-life care.mp.
9. patient care planning.mp. or Patient Care Planning/
10. critical illness.mp. or Critical Illness/
11. decision making.mp. or Decision Making/
12. or/1-11
13. physician-patient communication.mp.
14. Communication/ or communication.mp.
15. interpersonal relations.mp. or Interpersonal Relations/
16. nurse-patient relations.mp. or Nurse-Patient Relations/
17. physician-patient relations.mp. or Physician-Patient Relations/
18. or/13-17
19. 12 and 18
20. (comment or letter or editorial or note or erratum or short survey or news or newspaper article or case report).mp. or historical article.pt.
21. exp Meta-Analysis as Topic/
22. meta-analysis.pt.
23. (meta analy\$ or metaanaly\$).tw.
24. (systematic review\$ or pooled analy\$ or statistical pooling or mathematical pooling or statistical summar\$ or mathematical summar\$ or quantitative synthes\$s).mp. or quantitative overview.tw.
25. (systematic adj (review\$ or overview\$)).tw.
26. (exp review literature as topic/ or review.pt. or exp review/) and systematic.tw.
27. or/21-26
28. (cochrane or embase or psyclit or psycinfo of cinahl or cinhal or science citation index or scisearch or bids or sigle or cancerlit).ab.
29. (reference list\$ or bibliograph\$ or hand-search\$ or relevant journals or manual search\$).ab.
30. (selection criteria or data extraction or quality assessment or jadad scale or methodological quality).ab.
31. (study adj selection).ab.
32. 30 or 31
33. review.pt.
34. 32 and 33
35. 20 or 27 or 28 or 29 or 34
36. 19 not 35
37. limit 36 to english language
38. limit 37 to yr="1998 - 2015"

EMBASE

1. critically ill patient.mp. or critically ill patient/
2. life sustaining treatment.mp. or life sustaining treatment/
3. palliative therapy.mp. or palliative therapy/
4. patient care planning.mp. or patient care planning/
5. terminal care.mp. or terminal care/
6. treatment planning.mp. or treatment planning/
7. patient care.mp. or patient care/
8. health care planning.mp. or health care planning/
9. living will.mp. or living will/
10. medical decision making.mp. or medical decision making/
11. clinical decision making.mp. or clinical decision making/
12. patient decision making.mp. or patient decision making/
13. advance care planning.mp.
14. acp.mp.
15. goals of care.mp.
16. goc.mp.
17. advance directives.mp.
18. or/1-17
19. interpersonal communication.mp. or interpersonal communication/
20. decision support system.mp. or decision support system/
21. communication skill.mp. or communication skill/
22. doctor-patient relation.mp. or doctor patient relation/
23. nurse-patient relation.mp. or nurse patient relationship/
24. or/19-23
25. 18 and 24
26. (comment or letter or editorial or note or erratum or short survey or news or newspaper article or case report).mp. or historical article.pt.
27. exp "meta analysis (topic)"/
28. meta-analysis.pt.
29. (meta analy\$ or metaanaly\$).tw.
30. (systematic review\$ or pooled analy\$ or statistical pooling or mathematical pooling or statistical summar\$ or mathematical summar\$ or quantitative synthes\$s).mp. or quantitative overview.tw.
31. (systematic adj (review\$ or overview\$)).tw.
32. (exp review literature as topic/ or review.pt. or exp review/) and systematic.tw.
33. (cochrane or psyclit or psychinfo or cinahl or cinhal or science citation index or scisearch or bids or sigle or cancerlit).ab.
34. (reference list\$ or bibliograph\$ or hand-search\$ or relevant journals or manual search\$).ab.
35. (selection criteria or data extraction or quality assessment or jadad scale or methodological quality).ab.
36. (study adj selection).ab.
37. review.pt.
38. or/26-37
39. 25 not 38
40. limit 39 to english language
41. limit 40 to yr="1998 - 2015"

Appendix 5: Outcomes of Interest

QUESTION 1: What tools enable providers to *introduce* advance care planning or goals of care discussions?

Provider Outcomes:

- Confidence in introducing ACP/GoCDs
- Comfort with introducing ACP/GoCDs
- Frequency of introducing ACP/GoCDs
- Knowledge of how to introduce ACP/GoCDs

Patient Outcomes:

- ACP/GoCD being introduced
- Patient quality of life
- Other patient experience measures
- Patient illness understanding
- Any reported patient benefit
- Patient satisfaction with the process
- Was SDM involved or informed
- Are patient wishes being followed

Population-based Outcomes:

- Care at EOL (e.g., hospitalizations, feeding, life support, codes, etc.) - are they changing on a population level?

QUESTION 2: What tools enable providers to *facilitate* advance care planning or goals of care discussions?

Provider Outcomes:

- Confidence in facilitating ACP/GoCDs
- Comfort with facilitating ACP/GoCDs
- Frequency of facilitating ACP/GoCDs
- Skill development in facilitating ACP/GoCDs
- Competency in facilitating ACP/GoCDs

Patient Outcomes:

- ACP/GoCD
- Patient quality of life
- Other patient experience measures
- Patient illness understanding
- Any reported patient benefit
- Any reported patient values
- Patient satisfaction with the process
- Was SDM involved or informed
- Are patient wishes being followed
- Code status [e.g., Do Not Resuscitate (DNR), Do Not Attempt Resuscitation (DNAR), Allow Natural Death (AND)]
- EOL interventions
- Life-sustaining therapies
- Levels of care

Population-based Outcomes:

- Care at EOL (e.g., hospitalizations, feeding, life support, codes, etc.) - are they changing on a population level?

QUESTION 3: What tools are best suited for *documentation* of advance care planning or goals of care discussions?

Provider Outcomes:

- Completion of ACP/GoCD forms
- Submission of ACP/GoCD forms
- Content elicited from the ACP/GoCDs and documented
- Communication/sharing of ACP/GoC wishes with SDM
- Communication/sharing of ACP/GoC wishes with other healthcare providers

Patient Outcomes:

- ACP/GoCDs being introduced
- Patient quality of life
- Other patient experience measures
- Patient illness understanding
- Any reported patient benefit
- Any reported patient values
- Patient satisfaction with the process
- Was SDM involved or informed
- Are patient wishes being followed
- Code status (e.g., DNR, DNAR, AND)
- EOL interventions
- Life-sustaining therapies
- Levels of care

Population-based Outcomes:

- Care at EOL (e.g., hospitalizations, feeding, life support, codes, etc.) - are they changing on a population level?