



**State of the Science Review**

**of**

**Advance Care Planning models**

*A project funded by*

*the Australian Government,*  
*Department of Health and Ageing*  
*with the Respecting Patient Choices Program*

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# State of the Science

## Key Recommendations

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**Advance Care Planning discussions should be the right of every Australian and not an option offered to a few.**

**Advance Care Planning requires:**

- an ongoing values-directed discussion involving health professionals, clients, and family,
  - a transformation of systemic processes to support ACP across a range of institutional settings
  - adequate funding and support to normalise ACP into clinical practice and culture
  - the targeted involvement of specific cultural communities and the wider public. and
  - excellent education and applied research to guide this process.
- 

**System Policies, Standards and Processes:**

It is recommended that:

- Adequate funding and support is made available to embed ACP programs in clinical culture.
  - Government agencies promote the national uniformity of legislation, policies, and guidelines underpinning ACP. In particular, government agencies are to:
    - ◆ develop guidelines focusing on ACP documentation, coding, and protocols,
    - ◆ promote and make available legally valid forms and documents, and
    - ◆ introduce financial incentives tied to high quality ACP outcomes.
    - ◆ In the absence of consistent government regulation, hospitals and nursing homes develop, implement, and adhere to rigorous and consistent ACP policies and guidelines.
  - ACP interventions should have a system-wide focus and address educational, systemic, and cultural concerns as well as community involvement issues.
    - ◆ Enrolling in or leaving any program of care within the health system should routinely lead to a review and documentation of ACP.
  - Quality improvement initiatives based on well designed evaluation and feedback systems are implemented.
    - ◆ Health care facilities should audit rates and work towards 100% completion and transfer of plans.
-

- ◆ Patients' EOL treatment choices are recorded in medical charts and made available to patients, agents and relevant health professionals across settings.
- ◆ Simple validated audit tools are used to enhance the functionality of administrative systems.
- ◆ Hospitals regularly check the accuracy of ACP protocols.

## **Staff Roles & Responsibilities:**

It is recommended that:

- Health professionals regard ACP as an ongoing communication process that:
  - ◆ begins as early as possible in a patient's illness trajectory,
  - ◆ is embedded in clinical routines and professional practice,
  - ◆ is preceded by a screening process that assesses the capacity of people with dementia to complete advance care plans,
  - ◆ develops documentation that is clear, relevant and consistent with patients' hopes and choices, and
  - ◆ effectively involves agents to assist them to understand their role in the process
- Physicians initiate ongoing ACP discussions that:
  - ◆ involve patients, family members, and substitute decision makers (agents) and
  - ◆ counsel patients and family members about illness trajectories, probable treatment outcomes, as well as the options and choices they are facing.
- Nurses and allied health staff routinely monitor and re-assess patients' unmet ACP needs. In particular, they:
  - ◆ check a patient's ACP status for congruence between patients' stated wishes and actual care and
  - ◆ facilitate ACP discussions where appropriate.
- Emergency workers are trained to routinely ask about ACP documentation and follow it.

## **Educational Processes:**

It is recommended that:

- Education programs be designed to improve
  - ◆ knowledge of ACP,
  - ◆ expertise in conducting an ACP discussion
  - ◆ completion rates of documentation

- Continuing education programs provide staff with mentoring and skill development
- Educational programs be subject to evaluation and quality improvement

## **Research:**

It is recommended that:

- Researchers and research funding bodies address the gaps in the literature on ACP and, in particular:
  - ◆ the ACP needs of patients on different illness trajectories,
  - ◆ the factors that affect implementation, success, and sustainability of ACP programs, and
  - ◆ the components of the system-wide model and generating evidence regarding their transferability.

## **Community Health Promotion:**

It is recommended that:

- Stakeholders and Government agencies encourage and promote community-based discussions/education interventions.
- ACP be promoted as an activity for healthy adults
- Programs are developed that respond to the needs of minority populations.

# 1. Introduction

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An aging population combined with a rise in the scope and uptake of medical treatments has translated into an increased demand for excellent end-of-life care. New technologies have substantially extended the life expectancy of Australians but technical advances do not always equate to quality care or quality of life. New technologies tend to be expensive and potentially represent a heavy financial burden for the national health system, but more importantly, they are often not desired by patients or their families.

Advance care planning (ACP) is directed at improving quality of care, facilitating patient self-determination and reducing unwanted and unwarranted medical treatments and hospitalisations. By respecting every person's right to autonomy, dignity and fully informed consent, health professionals can assist individuals to reflect upon, choose and communicate their wishes regarding their current and future health care.

ACP is a consultative and ongoing process that enables patients to choose future health care options, which meet their personal lifestyle goals. Health care providers, family members and other important people in the lives of patients can collaborate in this process.

## 1.1 Background to the review

Over the course of the last decade, Advance Care Planning (ACP) has become a major field of study. It has its roots in a prolonged political, legal, and ethical battle that has its origin in the consumer rights movements of the late 1960s, which aimed to limit the amount of unwanted, aggressive medical interventions at the end of a patient's life. It was during that era that the Living Will first emerged. By the end of the 1970s, most U.S. states had ratified pieces of legislation that enabled patients to record end-of-life (EOL) treatment decisions in the form of Living Wills, do not resuscitate (DNR) orders, or do not hospitalise (DNH) orders. The appointment of substitute decision makers through the completion of durable power of attorney for health care forms entered the U.S. legislation during the 1980s. With the passing of the Patient Self-Determination Act (PSDA) in 1991 the use of such orders, the appointment of substitute decision makers, as well as the possibility of the withdrawal of life support was signed into U.S. federal law (Brown 2003). Until the late 1980s, debates about ACP used largely the terms such as 'Living Wills' and 'Do not resuscitate order'. Several important ACP interventions, such as the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) or the Wisconsin study, were already piloted during the 1980s. The following table (Table 1) gives a brief chronological overview of how the ACP literature evolved.

**Table 1: An historical overview of research concerns and findings**

<b>PERIOD</b>	<b>FOCUS</b>	<b>RESEARCH CONCERNS &amp; FINDINGS</b>
<p><b>1989-1993</b> <b>(1991 PSDA)</b></p>	<p>Ascertaining and documenting treatment choices</p>	<p>Legal and ethical status of AD Issues in uptake, implementation and outcomes of ADs</p>
<p><b>1993-5</b> <b>Post-Patient Self Determination Act</b></p>	<p>Poor uptake Education is the answer Identifying barriers Testing simple interventions</p>	<p>Better knowledge associated with higher levels of education, income &amp; white race Serious communication gap between health professionals and patients Quick-fix educational interventions don't work ADs not accessible or actively disregarded by physicians. Treatment-specific AD supported by proxy and physician –patient discussion = best outcomes</p>
<p><b>1995</b></p>	<p><b>SUPPORT study</b> to improve End-Of-Life care <b>Oregon 'Dying with Dignity Act'</b></p>	<p>AD alone are not the answer as operational and legal factors are crucial Improve decision-making through better communication and more comprehensive advance care planning. Spawned more information on EoL and palliative care choices</p>
<p><b>1995-9</b> increase in international papers</p>	<p>Fragmentation of field as contributors lost touch with issues</p>	<p>AD implementation was paperwork focused, patients were in need of physical and psychological comfort Many studies repeated work on legal and ethical status uptake, barriers and compliance with ADs</p>
<p><b>1998</b></p>	<p><b>'Respecting Choices'</b> Wisconsin</p>	<p>Respecting Choices = 85% prevalence of ADs in community, 95% in medical records, 98% compliance with ADs</p>



PERIOD	FOCUS	RESEARCH CONCERNS & FINDINGS
2000-1	Broaden scope to include social workers, nurses and ethics teams with focus on prevalence of ADs as outcome measures.	<p>Increased linking of ADs to a palliative approach and need for fundamental systemic &amp; cultural change</p> <p>Decision making bias of physicians and surrogates</p> <p>Development of decision making tools</p> <p>Prevalence of ADs as the outcome measure not satisfaction with process or compliance with patient wishes</p> <p>Patients start holding physicians legally accountable</p>
2002-3	More nuanced approaches – systematic reviews qualitative studies response shift	<p>Significant insights into patient issues re uptake, preferences &amp; communication dynamics.</p> <p>Focus on quality of life expectations and not just uptake</p> <p>Still no real outcomes from medical education</p> <p>Wide range of communication tools and interventions</p>
2004-6	Focus on tools, models and patient outcomes with different populations and illness trajectories	<p>Insight that different illness profiles require a more differentiated approach (Dementia, Chronic, Acute).</p> <p>Reports of successful implementation of ACP (Wisconsin, Oregon) reveal some of the key 'drivers' of organisational, systemic, and cultural change.</p> <p>Explorative research highlights the influence of politics and Media on popular perceptions of CPR, thus, shaping EOL decisions.</p> <p>Intense focus on specific systemic areas or organisational units (ICU, nursing homes) to generate value consensus and to mobilise professionals.</p>

## 1.2 Paradigm Shift

The most important paradigmatic shift in the literature on ACP occurred during the first half of the 1990s. Relatively simple, patient-focused interventions gave way to more complex, continuously evolving interventions that aimed to integrate ACP into the systemic as well as culturally anchored routines throughout the health care system. Pivotal to this change are the various publications inspired by the SUPPORT study, a well-designed, well resourced (US\$ 28 million) and ambitious intervention geared to increase AD completion rates. The SUPPORT study spectacularly failed to increase AD completion rates. However, the study made several important contributions to the field. On the one hand, the study made it absolutely clear that EOL care could be improved. On the other, the study also demonstrated that ACP interventions that focus on individual, patient-level decision-making are unlikely to generate the kind of quality improvements in EOL care that are expected of ACP. Joanne Lynn, one of the key authors of the SUPPORT study, puts this down to the inadequacies in the shared decision-making model. She suggests that contrary to at the time widely held assumptions:

- patient preferences are not stable nor are they easy to record,
- EOL care often does not involve decisions but is dictated by systemic and cultural routines,
- seriously ill patients/surrogates often do not want to face hard decisions, and
- participants are often unwilling to use information based on rational, decision-analytical approach (Lynn, Arkes et al. 2000).

In summary, Lynn, Arkes et al. argue that “improving patient-physician communication cannot ameliorate shortcomings in care; improvement requires restructuring the entire system” (2000).

Although such insights are often ignored by contributors to the burgeoning field who continue to employ the shared decision-making model, several programs that espoused a system-wide approach are increasingly regarded as benchmarks in ACP. Among those are the Respecting Choices® program implemented in La Crosse Wisconsin, the Oregon experience, as well as several other palliative care programs supported by the Robert Wood Johnson Foundation. Whereas in most other regions of the U.S., AD completion rates are in the vicinity of 15% to 25%, the La Crosse experience generated an 85% AD completion featuring a 95% prevalence of ADs in medical records (Hammes and Rooney 1998). The La Crosse experiment, treating ACP as an ongoing community-based discussion about values and preferences clearly demonstrated that a relationship-building, cooperative trans-services approach can significantly improve ACP as well as end-of-life outcomes. Another remarkable program had been developed in Oregon. Key to the Oregon experience was an extensive campaign covered extensively by the local media as well as a set of tools such as the

Physician Orders for Life-Sustaining Treatment (POLST), a medical chart system recording EOL treatment choices that substantially increased the compliance with patients' wishes by making them more accessible to health care professionals (Tolle, Tilden et al. 1998). Unfortunately, these programs have not been evaluated in a systematic fashion and although we do know that they are highly successful, we cannot be certain which program or contextual variables are salient features of their success.

### **1.3 Key issues guiding the structure of the review**

This lack of systematic evaluations of key models and programs in conjunction with other important knowledge gaps in the literature significantly influences the overall structure of this review. In fact, some of the most important insights, as for instance, provided by Joanne Lynn in the above-mentioned statement, are not the direct outcome of scientific studies but are the result of reanalyses of previous research interventions. If we would have conducted a systematic review, we would have most definitely missed these important, research-based expert opinion pieces. Instead, we decided to conduct a 'state of the science review' so as to screen more widely for relevant contributions to the field.

This 'state of the science review' is based on an extensive literature search using Medline, Proquest, CINAHL and Google Scholar. Articles were recorded in Endnote files and a team of researchers conducted a first pre-selection yielding 1645 articles. The records were chronologically ordered, coded and duplicates were eliminated. Inclusion criteria informed by operational relevance were devised and 1291 articles were eliminated. The remaining 346 articles were reviewed and ranked. The top ranking contributions were assessed by a second reviewer and differences in opinion were reconciled. A total of **1645** studies, research-based expert opinions, and systematic reviews inform this report.

### **1.4 Review Aim and Structure**

The overall aim of this **'State of The Science Review'** is to map and evaluate the available international evidence of the efficacy of advance care planning models of care.

An examination of the best evidence available will facilitate an effective and efficient knowledge transfer of this evidence into practice, and prevent duplication of research and practice effort around Australia.

This report is not a systematic review. Various problems that we encountered while reviewing the literature prompted us to broaden the focus beyond the scope of a systematic review. Pivotal in this decision was the fact that many contributions, albeit of central importance because of their innovative capacity, were underpinned by weak research. A highly focused systematic review would have discarded such contributions and, as a result, missed the central intellectual impulses that have guided the field over the last decade. In fact, poor quality research and lack of methodological rigor were the most common problems we encountered in the Review. The sophisticated well-executed research projects found in the

Review were focused on largely academic questions and added little in terms of explanatory value. Similar inadequacies can be found in the larger research area of palliative care of which ACP is only a small and relatively new sub-field. In a recent publication, Joanne Lynn (2005), writes about her involvement in a State Of The Science Review of palliative care in the following terms:

*“The review was worded as optimistically as possible, but the science was indefensibly inadequate on virtually every issue, from measuring better and worse outcomes of care to assessing the merits of standard therapy. I came away feeling that this must have been the state of science regarding heart disease fifty years ago – when most of the “science” was expert opinion and much of it was inadequate, even erroneous.” (Lynn 2005)*

Lynn’s insightful quote suggests that much of the field of end-of-life care is under-researched. In the light of this, it should come as no surprise that the literature on advance care planning is still dominated by conceptual literature and opinion pieces that are inadequately supported by scientific studies. Indeed, the literature features ‘models’ that are considered as ‘best practice’ by some U.S.-based foundations. The problem here is that although it is evident that these models work, very little is known about their salient features, nor about the roles played by independent and contextual variables. In other words, because we do not know which of the program components are responsible for the success of the intervention, we cannot predict with certainty the outcome of these models. Claims to their replicability, to date, hinge on applications of these models elsewhere that, in turn, have not been systematically evaluated.

Furthermore, although a number of seemingly successful interventions are described in the literature, when following the data trail it becomes apparent that such projects often disappear from the health services environment, raising the question of sustainability. Again, there is very little evidence available that could guide attempts to design sustainable programs. Past research has produced clusters of knowledge around certain issues, often duplicating the findings of research teams, while completely ignoring key research questions. This uneven coverage has been exacerbated by conceptual and methodological weaknesses producing a field of knowledge that provides little in terms of a systematic evidence base. In the light of these constraints, it was decided to conduct a ‘state of the science review’ focusing on the implementation of advance care planning programs in order to collect and evaluate available evidence that can be translated into practice.

In summary, the key concerns that guided the Review were

- substantial gaps in the research coverage of the field
- methodologically rigorous randomised control trials that had little explanatory value for models of care

- poor quality research and lack of rigor
- conceptual articles and opinion pieces provided the guiding intellectual impulses
- some methodologically weak research that made a contribution in terms of innovation
- research clustered around certain areas of interest to academic researchers
- large amount of duplication
- a number of descriptive models that are considered best practice' without empirical evidence
- insufficient evidence regarding the salience of program components making outcome predictions impossible
- insufficient evidence regarding sustainability of reported models.

## 2. Review of Methodology

This is a study about the available evidence underpinning the successful implementation of advance care planning programs. Because of its focus on implementation, the study excludes several subfields of study that provide the context to advance care planning interventions. Hence, studies dealing with

- the knowledge and attitudes of patients, carers, and health professionals,
- the reasons why people complete or reject advance care planning documents,
- the cultural, religious, or ethnic determinants influencing end-of-life treatment choices,
- the capacity of patients to make end-of-life treatment choices,
- patient treatment preferences,
- surrogate decision making,
- the stability of end-of-life treatment choices,
- measuring the experiences of making ACP choices,
- ethical considerations,
- legal considerations,
- basic historical or background information,
- philosophical discussions of ACP, as well as
- the application of ACP principles to other medical fields

were excluded from this review.

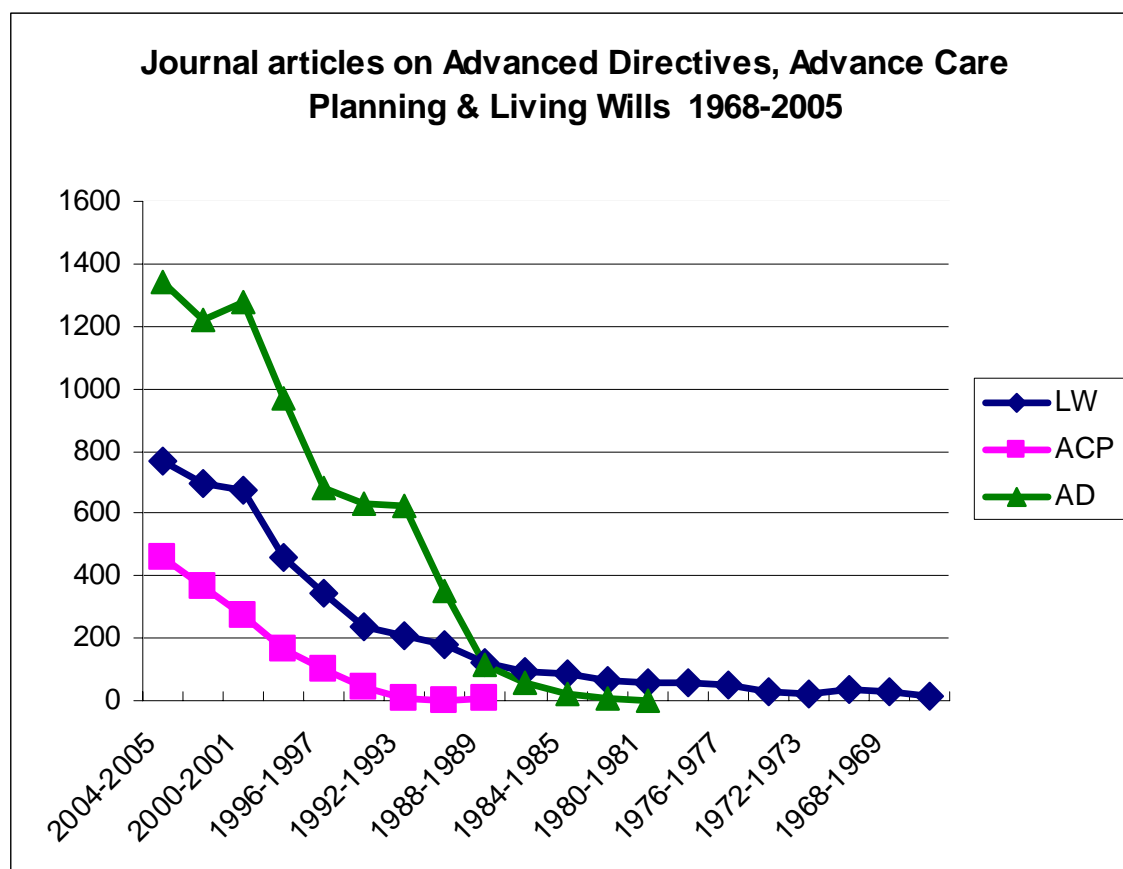
A full review of these studies would have been beyond the scope of this review.

### 2.1 Search Strategy

Preceded by debates focusing on particular instruments such as 'Living Wills' or 'Do Not Resuscitate' (DNR) orders the debate surrounding Advance Directives (AD) took shape during the mid 1980s. However, during the second half of the 1990s contributions to the field of advance care planning grew exponentially amounting to several thousand articles. Chart 1 gives a visual overview of the development of the field.

## Search Strategy

Chart 1 Increase in ACP articles 1968-2005



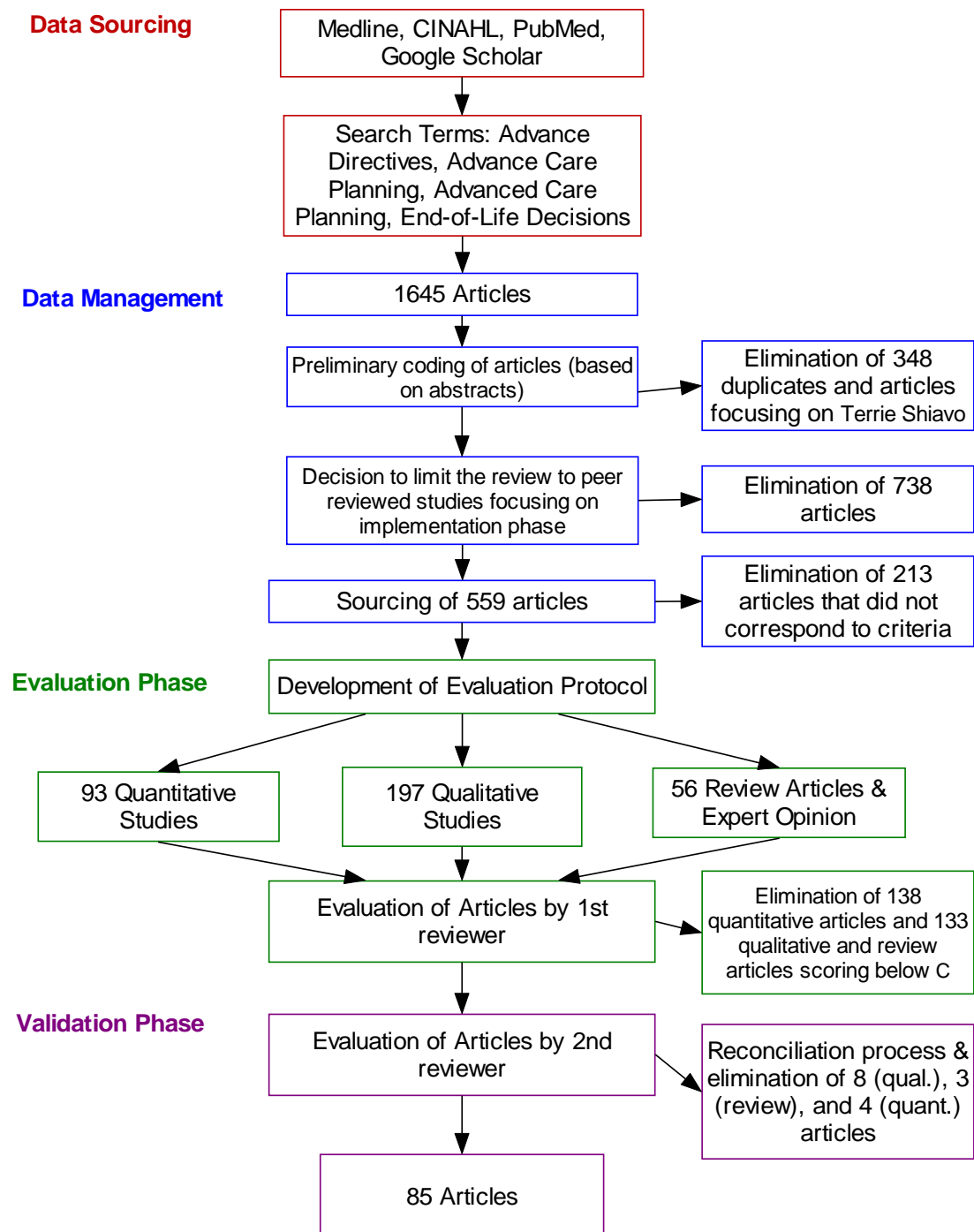
Legend: LW = Living Wills. ACP = Advance Care Planning. AD = Advance Directives

Although Google Scholar hits do not directly translate into discrete scientific publication, they do give a very rough indicator of the volume and exponential growth of publications to the field. In order to make the task more achievable and meaningful some basic criteria were devised to limit the search. As the overall aim of the project was to distilling a best practice model for ACP within an oncology setting it was decided to use operational relevance as a guiding frame of reference. Thus, articles that dealt more generally with End-of-Life care and not specifically with ACP were excluded.

## Flow Chart of search strategy

Chart 2 provides an overview over the search strategy employed:

### Chart 2 Search Strategy





## Data base searches

An extensive literature search utilising Medline, Proquest, and CINAHL was conducted. These databases often provide the basis of literature searches because they capture exclusively refereed journal articles. However, while conducting the literature search it soon became evident that articles widely discussed in the literature did not show up in the search results. As a result, it was decided to use Google Scholar in order to locate items not contained within the three databases. Google Scholar gave us more practice-based journals that practitioners tend to publish in. Indeed, in the absence of a more systematically charted research field, the contributions of practitioners such as conceptual or opinion pieces as well as educational case studies became a central reference point for many researchers. Within the context of this report, expert opinions are essentially research-based studies - contributions of practitioners who base their claims on interventions they conducted in the past. In this sense, expert opinions are comments that re-analyse and develop further the insights of that work giving rise to a form of expert consensus (however, no consensus statement is currently available in ACP). The databases that were accessed in conjunction with the main search terms employed are given in the following Table (Table 3).

**Table 3: Databases and Search Terms**

Databases	Search Terms
MedLine	<ul style="list-style-type: none"><li>■ Advance Care Planning,</li><li>■ Advance Directives,</li><li>■ Advanced Directives, and</li><li>■ End-of-Life Decisions.</li></ul>
Proquest	
Cinahl	
Goggle Scholar	

The literature search was limited to articles published between January 1989 (the year the PSDA was passed in the U.S.A.) and July 2006.

## 2.3 Evaluation Process

A total of **1645** references were collected for a potential inclusion into this report. The references were divided into 18 preliminary categories and stored in Endnotes files. Exclusion criteria were narrowed and the above-mentioned subfields as well as duplicates were eliminated leaving a total of 346 articles to be reviewed.

Of these, **93** were qualitative studies, **197** were quantitative studies, and **56** were review articles/expert opinions. Evaluation protocols for each of these three categories were devised using the guidelines issued by the McMaster University Occupational Therapy Evidence-Based Practice Research Group (Law, Stewart et al. 1998) as well as the evaluation tools developed by the University of Salford's Health Care Practice Research and Development Unit (<http://www.fhsc.salford.ac.uk/hcprdu/tools.htm>).

The articles were evaluated by a reviewer and ranked according to research quality and intellectual innovation. A four letter scale (A-D) was used for the ranking process. Sixteen qualitative and review articles and 59 quantitative studies were retained (scoring A or B) during the evaluation process, leaving a total of 85 articles.

## 2.4 Validation Process

Articles ranked A or B were validated by a second reviewer. Evaluative differences were subsequently reconciled through a peer moderation process.

Contributions deemed to be of sufficiently high quality to be included in this review were recoded applying one of the categories outlined in the following table (List 1).

### List 1 Code Categories

TOPIC	CODE
<b>Shared Decision Making</b>	
Uptake	DM-U
Capacity	DM-C
Medical	DM-M
Tool	DM-T
Outcome	DM-O
Barriers	DM-B
<b>Implementation Process</b>	
Education	I-E
System-wide	I-SW
- Models	I-M
Outcomes	I-O
Information	I-I
Tools	I-T
Barriers	I-B
<b>Communication Process</b>	
Model	Com-M
Values-Classification	Com-VC
User	Com-U
<b>Conceptual Considerations</b>	
Expert Opinion	C-EO

# Strength of Evidence of the Literature

Key Q1 = quantitative studies  
Q2 = qualitative studies and reviews

SPECIFIC AIM	SAMPLE POPULATION	RESULTS	IMPLICATIONS	QUALITY
<b>1. Impact of ADs</b>				
To report on changes in ACP with Patient Self-Determination Act (PSDA) and other events in nursing homes in 10 states (Teno, Branco et al. 1997).	Pre (n=2175)-Post (n=2088) Observational Cohort Study with 6 months follow up.	Significant increase in ADs. Yet striking variations between states. Majority of nursing home residents do not have ADs.	With the implementation of the PSDA, there was a modest increase in documentation of living wills.	Q1-A
To assess the effectiveness of written ADs in the care of seriously ill, hospitalised patients in the aftermath of the PSDA and SUPPORT (Teno, Lynn et al. 1997).	Observational Pre-Post PSDA Cohort Study + Randomised Controlled Trial during Post phase. (n=9105)	ADs did not substantially enhance physician-patient communication or decision-making about resuscitation. The lack of effect was not altered by PSDA or enhanced by SUPPORT although these interventions increased documentation of existing ADs.	Future work to improve decision making should focus upon improving the current pattern of practice through better communication and more comprehensive ACP.	Q1-B
Examining the relationship of AD to decisions about resuscitation (Teno, Lynn et al. 1994).	Observational Study (n=3058) using interviews of people with serious illnesses.	ADs had no clinically important effect on decision-making about resuscitation.	Need to bear in mind the functionality of ADs and not only their completion rate.	Q1-B
Examine usefulness of educational videotape as a means to promote AD (Cugliari, Sobal et al. 1999).	Cohort Study (n=419, intervention = 204, control = 215): Interviews with patients to be admitted to two teaching hospitals.	Video was effective but did not increase AD completion rate or intention to complete ADs.	Video tapes could be useful as component of a multifaceted efforts to promote ADs.	Q1-C
Examine whether executing ADs is associated with enhanced communication between patients & their physicians on these issues (Virmani, Schneiderman et al. 1994).	Structured interviews with 115 seriously ill cancer patients and 22 of their physicians.	Only 30% of patient claimed that they had discussed ADs. If discussion took place it did not address treatment options.	ADs by themselves do not stimulate discussion between physicians and patients.	Q1-C

Evaluate use of ADs in patients undergoing pancreaticoduodenectomy & esophagectomy (Yang, Bentrem et al. 2004).	Chart Review (n=252)	More patients that have major surgery have ADs but the number of medical records remains low.	Further attention to ADs would foster increased communication between surgeons and patients and extend patient autonomy.	Q1-D
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SPECIFIC AIM	SAMPLE POPULATION	RESULTS	IMPLICATIONS	QUALITY
<b>2. SUPPORT</b>				
Evaluate whether lack of effect of ADs on decision-making in SUPPORT study might arise in part from the content of the actual documents (Teno, Licks et al. 1997).	Chart review of 4804 SUPPORT patients.	ADs placed in medical records of seriously ill patients often did not guide medical decision-making beyond naming a health care proxy or documenting general preferences in a standard living will format.	Need to improve the ways care plans evolve including effective and targeted ACP.	Q1-B
To assess the effectiveness of written ADs in the care of seriously ill, hospitalised patients in the aftermath of the PSDA and SUPPORT (Teno, Lynn et al. 1997).	Observational Pre-Post PSDA Cohort Study + Randomised Controlled Trial during Post phase. (n=9105)	ADs did not substantially enhance physician-patient communication or decision-making about resuscitation. The lack of effect was not altered by PSDA or enhanced by SUPPORT although these interventions increased documentation of existing ADs.	Future work to improve decision making should focus upon improving the current pattern of practice through better communication and more comprehensive ACP.	Q1-B
Review of published SUPPORT reports describing patient preferences & communication (Covinsky, Fuller et al. 2000).	Descriptive Review	Understandings of doctors, nurses, and surrogate of their patients' preferences is only moderately better than chance. Most patients do not discuss their preferences with their physicians, and only about half of patients who do not wish to receive CPR receive DNR orders.	The care provided to patients is often not consistent with their preferences and is often associated with factors other than preferences or prognoses. Improving these deficiencies in EOL care may require systemic change rather than simple interventions.	Q2 - C

SPECIFIC AIM	SAMPLE POPULATION	RESULTS	IMPLICATIONS	QUALITY
<p>To describe implication of SUPPORT study for nursing &amp; to speed up innovation (Rutledge, Donaldson et al. 2001).</p>	<p>Systematic Review of SUPPORT literature.</p>	<p>Outlines the major findings of SUPPORT and HELP studies.</p>	<p>It is difficult to change deeply entrenched patterns of EOL care,  Health providers need to help patients and family members to understand illness trajectories and treatment choices,  Health providers should initiate ACP discussions,  Screening for depression in seriously ill patients may allow for appropriate treatments and enhanced ACP decision-making,  A realistic counselling regarding probable outcomes of treatment choices may help patients/families to make decisions,  Administrative measures were needed to diminish variability in EOL care,  Given the incongruence of patients and surrogate preferences, it is important to have a patient's own reported perception of values and preferences,  Nurses could play a role in assessing patients for unmet ACP needs and check for incongruity between patients and physicians regarding treatment choices, and  Health providers need to ask specific questions about patient preference for treatments that are relevant to the patient's condition</p>	<p>Q2-A</p>
<p>Evaluate comparability of decisions in treatment of severely ill incompetent elderly patients among physicians &amp; nurses from a cross-cultural perspective (Richter, Eisemann et al. 2002).</p>	<p>Cross-sectional study (questionnaire with vignette) involving Swedish nurses (n=122) and physicians (n=104) and German nurses (n=182) and physicians (n=192).</p>	<p>With increasing amounts of information about patients' wishes, there is a tendency toward compliance with patients' wishes.</p>	<p>High numbers of health professionals would act against patients' wishes – nurses more likely to comply with patients' wishes. Swedish HPs place more importance on family wishes in their decision making than Germans.</p>	<p>Q1-B</p>

SPECIFIC AIM	SAMPLE POPULATION	RESULTS	IMPLICATIONS	QUALITY
Explores individual patient-level decision making for EOL care that provided epistemic basis for SUPPORT study (Lynn, Arkes et al. 2000).	Synthesis of findings from SUPPORT study	Many of the assumptions underlying the model of improved decision-making are problematic. The implementation of shared decision-making can be difficult. Practice patterns and social expectations may be strong influences in shaping patients' courses of care.	System-level innovation and quality improvement in routine care may offer more powerful opportunities for improvement.	Q2-B
<b>3. Patient-Health Professional Communication</b>				
Explore factors that influence execution of ADs (Ali 1999).	Structured, written Questionnaire (n=162) involving non-hospitalised elderly (60+). Test-retest reliability 0.85.	Most frequent cited reason for not executing ADs was physicians failure to discuss the issue. Most frequent cited reason for creating ADs was participants desire to participate in their end of life decisions.	Need to stimulate physician-patient AD discussions. Geriatric nurses can use strategies to enable both physicians and older adults to promote AD enactment. Geriatric nurses need to promote ADs in wider community.	Q1-A  Pre-SUPPORT
Assesses impact of discussions on advance directives on patients' satisfaction with their primary care physicians & outpatient visits (Tierney, Dexter et al. 2001).	Prospective cohort study of patients enrolled in a RCT (n=686) including 81 physicians.	Chronically ill patients are more satisfied with their primary care physicians & the care they deliver when ADs are discussed.	Need to discuss ACP with chronically ill patients.	Q1-B
Assess relationship between the documentation of a discussion of ADs and hospital charges for medicare patients during the last hospitalisation in the patient's life (Chambers, Diamond et al. 1994).	Retrospective Cohort (n=474), multivariate analysis	Unexpectedly, patients with & without ADs were not remarkably different. Substantial mismatch between what patients want to discuss about EOL treatment directive and decisions and what physicians do.	Cost savings may be possible if ACP discussions take place.	Q1-B
To evaluate the effect on an ACP intervention on the completion of ADs and patient satisfaction (Ho, Thiel et al. 2000).	Prospective Cohort Study (n=210), volunteer sample of people with HIV/AIDS	ACP increases the rate of AD completion but many completed ADs are legally invalid. ACP did not improve patient satisfaction with health care.	ACP cannot be justified with increased satisfaction with health care system.	Q1-B

To determine if educational intervention for nursing home physicians improve quality of dying for nursing home residents (Keay, Alexander et al. 2003).	Prospective study (n=61) with physicians caring for 203 residents in 5 nursing homes. 12 physicians participated in education program.	Intervention was effective in improving terminal care outcomes.	Important terminal outcomes can be significantly improved by targeting key nursing home physicians with an adult educational program that includes audit and feedback, and quality improvement suggestions.	Q1-B
<b>SPECIFIC AIM</b>	<b>SAMPLE POPULATION</b>	<b>RESULTS</b>	<b>IMPLICATIONS</b>	<b>QUALITY</b>
Assess effectiveness of an intervention to increase discussion & documentation of ADs. To evaluate whether intervention affected preferences for CPR & hospitalisation (DeLaGarza, Andersen et al. 2001).	Chart Review (n=4248) + Descriptive survey (n=6598) follow up of residents from 100 nursing home facilities in 6 US states.	Discussion & documentation of ADs can be increased with education of health care providers.  Racial & geographical differences in desire for life-prolonging treatment existed before and after intervention.	Education of health professionals can increase AD completion rates.	Q1-B
Explore how adults communicate their EOL preferences (McDonald, Deloge et al. 2003)	Questionnaire, using a convenience sample of 119 community dwelling non-institutionalised adults.	Findings show discussions about EOL preferences frequently lack the clarity and detail needed by significant others & health care providers to honour the preferences.	Routine dialogue with health care providers and family about EOL preferences might provide greater clarity and comfort about EOL preferences.	Q1-C
Determine relative impact of five proposed barriers to physician use of ADs (Morrison, Morrison et al. 1994).	Self-administered questionnaire (n=277) sent to attending physicians at NY hospital.	Lack of knowledge about implementing ADs & erroneous beliefs about their appropriateness were the strongest & most consistent barriers. Perceived time constraints & physician discomfort were significant barriers to discussions initiated by physicians.	Need to address physicians' erroneous beliefs regarding the appropriateness of ADs, as well as other barriers.	Q1-C
Exploration of how attending physicians in outpatient practices discuss ADs with their patients (Tulsky, Fischer et al. 1998).	Observational Study (n=56) involving 56 patient/physician pairs in an out clinic.	ACP discussions are of poor quality. A schedule for ACP discussions is offered.	Need to improve the abilities of physicians, patients, and families to make ACP choices.	Q1-C
<b>4. Education Strategies</b>				



<p>Evaluation of the effectiveness of a 5-10 min discussion designed to foster dialogue between patients and their proxies in a preoperative evaluation clinic (Grimaldo, Wiener-Kronish et al. 2001).</p>	<p>RCT (n=200), control, intervention.</p>	<p>Preoperative intervention significantly increased discussions between patients &amp; their proxies. Increase was statistically &amp; clinically significant.</p> <p>Anaesthesia preoperative evaluation can be another opportunity to encourage patient &amp; proxy communication about EOL care.</p>	<p>The preoperative evaluation period can be an opportunity to encourage patient and proxy communication about EOL care.</p>	<p>Q1-A</p>
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SPECIFIC AIM	SAMPLE POPULATION	RESULTS	IMPLICATIONS	QUALITY
Educational and motivational interventions to promote ACP in Department of Veterans Affairs out-clinics (Pearlman, Starks et al. 2005).	RCT (intervention n= 119, control n= 129), 55+	Positive outcome regarding increase in ACP discussions, filing of ADs in medical records. HP-patient higher agreement for treatment preferences, values, and personal beliefs.  Agreement scores for proxy-patient did not differ between groups – but were higher for personal beliefs.	The intervention demonstrates mixed results and highlights complexity of ACP.	Q1-A
To evaluate the feasibility and effectiveness of implementing a ‘Let me decide’ (LMD) AD education program (Molloy, Russo et al. 2000).	Randomised study (n=3x50), veterans living in the community	The LMD intervention successfully educated 81% of participants, 63% completed ADs.	The systematic implementation of the LMD ACP programs does affect willingness to complete ADs.	Q1-B
Review of education interventions to increase AD completions (Patel, Sinuff et al. 2004).	Systematic meta-analysis of RCTs (n=9) – no terminally ill patients in sample.	Advance Directive completion rates documenting patient preferences for end-of-life care may be increased by simple patient-directed educational interventions.	Simple patient-directed interventions may increase AD completion.	Q2-C
Describe implementation and resources and problems of implementation of AD in home care agencies (Gates, Schins et al. 1996).	Cross sectional study (n=80) of agencies.	Problems related to staff: Lack of knowledge or understanding regarding ADs increased client admission time and/or paperwork, visit work, legal implications.  Agencies reported greater effectiveness in educating staff about ADs than clients & families	Outlines barriers and raises questions regarding effective AD promotion targeting clients & families.	Q1-C
<b>5. Education Methodologies</b>				
To develop and evaluate an education program to help older people find out about treatment and care choices at the end of life (Sanders, Seymour et al. 2006).	Action Research-inspired peer education study	The education discussions and the related booklet were perceived as acceptable in providing information about a sensitive issue. Peer educators felt that the training course prepared them well.	Useful pilot study of the education program extended to other UK areas. The model is transferable. Participatory design can overcome obstacles encountered by top-down approach.	Q2-A

SPECIFIC AIM	SAMPLE POPULATION	RESULTS	IMPLICATIONS	QUALITY
To determine if educational intervention for nursing home physicians improve quality of dying for nursing home residents (Keay, Alexander et al. 2003).	Prospective study (n=61) with physicians caring for 203 residents in 5 nursing homes. 12 physicians participated in education program.	Intervention was effective in improving terminal care outcomes.	Important terminal outcomes can be significantly improved by targeting key nursing home physicians with an adult educational program that includes audit and feedback, and quality improvement suggestions.	Q1-B
Examined intervention to help high functioning community-dwelling older people to communicate their wishes for EOL care (Gutheil and Heyman 2005).	Post-test-only control group design (n=98), control group (n=44), intervention (n=54 - 27 elderly, 27 agents). Randomly assigned	For individual participants, there was a statistically significant difference b/w groups of knowledge of the health care proxy form & the roles & responsibilities of the agent.  For dyads there was a significantly higher mean communication score for intervention group than for control group.	It is possible to increase ACP communication through group intervention. Yet health providers must make effort to make time to encourage their patients to share with them their EOL choices. Providers must work on their own ability to be comfortable with such conversations & must be ready to honour choices.	Q1-B
Examine the effectiveness of group education session in increasing completion of Durable Power of Attorney for Health Care (DPAHC) or living wills (LW) (Dipko, Xavier et al. 2003)	Retrospective Cohort Review (intervention n=203, comparison n=13710), not randomised.	AD completion is associated with group education about ADs & with patient age.	Group education is an effective as well as time & cost-efficient social work tool for facilitating completion of ADs, particularly among older patients.	Q1-C
<b>6. Impact of Information Leaflets</b>				
Determine whether a standard family information leaflet (FIL) improved satisfaction & comprehension of information provided to family members of ICU patients (AZOULAY, POCHARD et al. 2002).	RCT, prospective (n=204) patients	FIL significantly improved comprehension.	ICU care givers should consider issuing an FIL to improve the effectiveness of the information they impart to families.	Q1-A
Whether requirement to distribute information to hospital patients increased completion of health care proxy. Explore factors that might influence use of ADs (Cugliari, Miller et al. 1995).	Interviews with randomly selected patients (n=419).	Patients were more likely to complete a proxy in the hospital that provided the form in advance of the day of admission indicating completion rates for ADs may be significantly increased by altering the time of information distribution prior to admission.	Although many patients would prefer to receive information about AD during an office visit with a physician, hospitalisation can provide a valuable opportunity for many patients to complete ADs.	Q1-B

SPECIFIC AIM	SAMPLE POPULATION	RESULTS	IMPLICATIONS	QUALITY
<b>7. ACP Competency of Health Professionals</b>				
Assess competence of medical residents to discuss ADs with patients using 2 measures – perceived competence & behavioural competence (Buss, Alexander et al. 2005).	Cross-sectional, self-report questionnaire (n=282). Some psychometrics provided.	Many residents consider themselves competent to discuss ADs with patients but fail to engage in recommended behaviour for such discussions.	Didactics have less and potentially negative impact on EOL skills. Experiential learning correlates with behavioural and perceived competence.	Q1-B
Describes Objective Structured Clinical Examination (OSCE), a tool to assess medical residents' knowledge and ability to address basic EOL issues (Aronson and Kirby 2002).	Descriptive, 40-44 residents	Advance directive OSCE is a useful initial assessment of knowledge & ability to address basic EOL issues.		Q1-C
Examine roles & AD communication practices of social workers as members of an interdisciplinary health care team (Black 2005).	Cross Sectional Study (n=135) with physicians (n=32), nurses (n=74), and social workers (n=29).	Social workers offer distinct skills in their AD communication practices and discuss ADs more frequently than either nurses or physicians.	Social workers are useful AD promoters in interdisciplinary health care team.	Q1-C
Provide preliminary description of social workers AD communication practices (Black 2004).	Self-administered questionnaire (n=29)	Social workers comprehensively address AD communication process.	Social workers are useful AD promoters within interdisciplinary health care team	Q1-C
Description of an educational module was developed for graduate medical residents about the care of dying patients to improve their communication skills, particularly in the area of EOL discussions with patients (McCann, Chodosk et al. 1998).	Description of module	The module has been a successful teaching aid.		Q2-C
<b>8. Capacity Assessment</b>				

<p>Develop a patient-centred approach for the assessment of competence to complete ADs of elderly people with cognitive impairment (Fazel, Hope et al. 1999).</p>	<p>Semi-structured interviews (n=2x50), 50 with dementia &amp; 50 elderly living in community.</p>	<p>Patient-centred approach for assessing competence to complete ADs can discriminate between normal &amp; dementia patients. Procedure has good interpreter &amp; test-retest reliability. Threshold score determined.</p>	<p>Provides quick competence assessment tool to be used in a variety of settings.</p>	<p>Q1-B</p>
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SPECIFIC AIM	SAMPLE POPULATION	RESULTS	IMPLICATIONS	QUALITY
Validate reference standards for assessment of capacity to complete an AD & to develop & test 3 simple screening instruments (Molloy, Silberfeld et al. 1996).	Randomly allocated trial (1 control, 1 intervention group) (n=96).	Health workers can make reproducible & valid assessments of capacity to complete an AD.  The SMMSE accurately differentiates people who can learn about & ultimately complete ADs from those who cannot.	Short simple screening instruments can be applied to people with a range of intellectual abilities & can categorise the capacity to complete ADs. A rigorous assessment should be undertaken to establish capacity to complete ADs in other areas.	Q1-B
Describe EOL process in nursing home (Cohen-Mansfield and Lipson 2003-2004)	Questionnaire (n=82), 3 groups, control group (n=59).	Many deaths do not involve a decision-making process immediately prior to death. Those that do differ from decision-making processes in which death is not imminent.	Study suggests that people with decisions made earlier (not prior to death) would be more likely to have a palliative care program.	Q1-C
Assessed physicians' discussions of ACP with patients with mild to moderate Alzheimers (Cavalieri, Latif et al. 2002).	Mail survey (n=63)	Physicians do not adequately address ADs with Alzheimers' patients & their care givers.	Physicians need to be more knowledgeable & proactive in approaches to ACP with Alzheimers patients.	Q1-C
Identify correlates of ACP in nursing homes (Allen, DeLaine et al. 2003).	Cross-sectional cohort study (n=78 residents & proxies)	Evidence that while most residents retain ability to state treatment preferences, many lack capacity to understand treatment situation or appreciate consequences of treatment choices made.  Resident capacity & global cognitive ability are not related to possession of ADs.  Proxy possession of ADs, proxy religiosity, & resident social engagement are related to residents' possession of formal ACP.	Greater attention to establishing clinically meaningful cut-off scores for aspects of capacity particularly in less verbal individuals, is needed.  Exploration of the potential differential impact of individual and proxy religiosity and/or spirituality on EOL medical decisions making is also needed.	Q1-C

SPECIFIC AIM	SAMPLE POPULATION	RESULTS	IMPLICATIONS	QUALITY
<b>9. Preferences</b>				
To elicit from patients themselves the aspects of treatment decisions-making most important to them when making end-of-life treatment decisions (Fried and Bradley 2003).	Qualitative Study of 23 patients, 60 years + with primary diagnosis of CHF, COPD, or cancer.	There are four major influences on treatment preferences: treatment burden and treatment outcome, variability in the assessment of treatment burden, uncertainty, and shifting valuations of treatment outcomes	A patient centred approach to ACP needs to incorporate a consideration of both treatment burdens and outcomes and the shifting perception of the likelihood of outcomes. Patient's valuation of these outcomes may change over time.	Q2-A
Compare patients & their surrogates scenario-based preferences with regard to life sustaining treatment (Lee, Smith et al. 1998).	Self-administered scenario Questionnaire (n=100) and retrospective medical chart review (n=96).	Patients make decisions about treatment when they are ill that are less consistent with the preferences on their AD than previous studies suggest.  Surrogates' decisions regarding treatment did not agree very well with patients' stated preferences.	ADs would be an effective means to preventing the unwanted use of CPR.	Q1-C
<b>10. Timing of ACP discussions</b>				
Evaluated ability of disease severity measures & recent clinical events to predict patient readiness for end-of-life issues (Pfeifer, Mitchell et al. 2003).	Cross-sectional study (n=100)	For chronic lung disease, objective disease severity & intensity of recent care are not associated with patient desire or readiness for EOL discussion	Physicians cannot use objective disease progression to predict which patients are most receptive to EOL discussions.	Q1-C
<b>11. ACP discussion - Tools</b>				
Initiate development of an instrument to assess readiness of patients to discuss advance care plans (Calvin and Eriksen 2006).	Content validity: 9 experts Reliability: 10 patients	Preliminary evidence of content validity & internal consistency reliability of the scale.		Q1-B
Reports on validation of Health Care Surrogate Preference Scale (Buckey and Abell 2004).	Content validity: pool of experts. Reliability: (n=188)	Evidence of good reliability, content, and factorial validity and preliminary evidence for construct validity. Limitation of weak supportive evidence for convergent construct validity.		Q1-B

SPECIFIC AIM	SAMPLE POPULATION	RESULTS	IMPLICATIONS	QUALITY
Describes the development and testing of a set of items (self-reporting) intended to measure the importance of several components posited to be critical to the concept of a good death to be used in EOL context (Schwartz, Mazor et al. 2003).	Self-reported questionnaire (n=596), 4 cohorts (undergraduate medical students, master's degree students in nursing, graduate students from the life sciences, hospice nurses)	The new Concept of a Good Death instrument appears to measure three distinct factors which people consider important to a Good Death. Ratings of the importance of these factors are reliable and valid.	Tool to quickly assess what people consider a good death.	Q1-C  Communication
<b>12. Medical Records</b>				
Determine whether nursing homes comply with residents' DNH orders (Dobalian 2004).	Retrospective cohort study, 815 responding facilities, 5899 eligible nursing home residents.	In general, nursing homes comply with DNH orders. However, some residents with DNH orders were hospitalised indicating the need for more rigorous policies.	Improved education regarding ADs, particularly DNH orders, is necessary for health care practitioners and patients. More consistent and rigorous policies should be implemented in nursing facilities.	Q1-A  Policy
Discusses serious, recurring, and generally unnoticed errors in planning for care near the end of life and possible steps toward improvement (Lynn and Goldstein 2003).	Case study, research-based Expert Opinion	Outlines basic mistakes in EOL care that lead to unwanted treatment	<p>Enrolling in or leaving any program of care should routinely lead to reviewing and documenting ACP. Facilities should audit rates and work toward 100% completion and transfer of plans. Medicare and other payers could compensate at a higher level those institutions that achieved this goal.</p> <p>Patients living with eventually fatal chronic illness should have a care team that stays with them through all settings. Facility-based clinicians can play important roles, but the continuity clinicians must remain involved since they know the patient, family, and living arrangements across time.</p> <p>Direct care staff whom the family comes to know and trust, should continue through difficult times, rather than switching with every change in payer.</p> <p>Documented plans should be available and understood across settings.</p> <p>Emergency care providers should regularly ask about ACP when serving very sick patients at home or in nursing facilities.</p>	Q2-A



SPECIFIC AIM	SAMPLE POPULATION	RESULTS	IMPLICATIONS	QUALITY
Examined the provision of PC for residents with a non-cancer diagnosis including the use of ADs as part of PC policies in residential aged care facilities in South Australia (Brown, Grbich et al. 2005).	Case studies (n=69) of residents in 90 randomly selected nursing homes.	Most residential care facilities used forms to record resident' wishes about EOL care. Some had no PC policy and few facilities required a formal AD. Not all residents had formally appointed proxy.	Nursing homes should be required to develop and implement a palliative care policy including a simple tool for ACP. Case referencing could assist in discussing ACP. Public education is essential to increase community and professional awareness to empower older people in nursing homes.	Q2 -B  Policy
Describe ACP and EOL care for nursing home residents (Happ, Capezuti et al. 2002).	Comparative analysis using data from a controlled clinical study (n=43)	Limiting ACP to cardiopulmonary resuscitation falsely dichotomised and oversimplified the choices about medical treatment and care at EOL, especially palliative care alternative, for these older nursing home residents. Formal hospice services were underutilised, and palliative care efforts by nursing home staff were often inconsistent with accepted standards.	Need for research and program initiatives in long-term care to improve and facilitate individualised ACP and palliative care at EOL.	Q1-B
Determine if use of a physician chart reminder improves rate of physician initiated discussion & subsequent completion of ADs in AIDS patients (Walker, Mandell et al. 1999).	RCT (n=84), 74 patients, 10 physicians.	Physician chart reminders are effective for promoting discussion & completion of ADs in patients with AIDS although the effect is physician-dependent.	Chart reminder demonstrates value of simple initiatives in influencing physician behaviour.	Q1-B
Examined an unstudied result of PSDA implementation: the use of institution-specific forms to document residents' treatment wishes (Bradley, Blechner et al. 1997).	Two stage stratified random sample (n=600) chart review of nursing home residents.	Nursing homes are complying with 'letter' of PSDA by providing written information about ADs at the time of admission.  Nursing homes frequently use institution-specific forms to document resident treatment choices.	Institutional forms may promote ADs if they are offered in combination with in depth ACP communication. Although wide-spread use of these forms suggests that ACP efforts are promoted by nursing homes, caution is recommended in using such forms in place of ADs or more comprehensive communication among health care providers, residents, and families about future treatment choices and decision making.	Q1-B

Determine whether presence of AD at admission to ICU influenced decision to initiate life support therapy in critically ill cancer patients (Wallace, Martin et al. 2001).	Secondary analysis of previously collected data. Matched pairs, case-control design (n=872), 236 with ADs, 135 with ADs were matched to 135 without ADs.	After controlling for type of malignancy, reason for admission to ICU, severity of illness & age, the decision to initiate life-supporting interventions did not differ significantly among patients with & without ADs. ADs may however have guided earlier treatment decisions.	Within an ICU context, ADs have little impact on decisions to initiate life-supporting treatment .	Q1-B
<b>SPECIFIC AIM</b>	<b>SAMPLE POPULATION</b>	<b>RESULTS</b>	<b>IMPLICATIONS</b>	<b>QUALITY</b>
Preferences & directives of severely ill dialysis patients/surrogates. Do these change over time? Is the plan chosen influenced by patients clinical & functional characteristics? Do ADP established correlate with clinical outcomes? (Anderson, Sikorski et al. 2006)	Retrospective chart review (n=109) and follow up of peritoneal dialysis patients admitted to a nursing home.	Plans could be established for almost all patients. Plans are sometimes modified when serious illness arose. Age & functional status strongly influence DNR & DNH orders.	ACP is often not decisive in determining treatment choices. Perhaps an alternative to ACP could prove more appropriate.	Q1-B
Whether AD was in patient's chart prior to death; where in chart; when & by whom acknowledgement was first initiated & at what stage of treatment was AD recognised (Badzek, Leslie et al. 1998).	Retrospective Chart Review (n=28), randomly chosen.	Chosen charts were often unavailable or did not contain ADs. ADs in charts included living will, medical power of attorney, both of these, and DNRs. Acknowledgement of ADs initially by resident physician.  Presence of AD first noted in patients chart about 5 days after admission or final event.	It is imperative that EOL decision documents be available and prominently visible to all persons involved in the care of seriously ill and/or dying patients.	Q1-C
To investigate the accuracy of one hospital's system to indicate whether an AD exists within a patient's medical record (Wallace and Desbiens 2004).	Medical record review (n=125)	Use of hospital's labelling system to indicate the presence of ADs was found to be highly inaccurate. Failure to correctly follow or understand the intended labelling procedure was the most likely source of error.	Hospitals should include plans to check the accuracy of protocols when they are adopted to ensure that they are performing as intended.	Q1-D
<b>13. ACP Barriers - Tool</b>				

Develop instrument that reliably measures barriers to AD implementation (BIAD) in different health care settings (Stiller, Molloy et al. 2001).	Questionnaire (n=79), nurses, physicians, social workers, health care aides.	The BIAD reliably measures barriers to AD implementation in different health care settings.	Will allow health professionals to develop targeted strategies to lower barriers.	Q1-C
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SPECIFIC AIM	SAMPLE POPULATION	RESULTS	IMPLICATIONS	QUALITY
<b>14. System-Wide Approach Models</b>				
Assess effect of a multi-component ACP intervention directed at nursing home social workers on identification & documentation of preferences for medical treatments & on patient outcomes (Morrison, Chichin et al. 2005).	Controlled Clinical Trial (n=139) nursing home residents	Intervention directed at nursing home workers significantly improved documentation & identification of patients' wishes regarding common life-sustaining treatments & resulted in higher concordance b/w patients' prior stated wishes & treatments received.	Larger study is required to determine whether these results are generalisable to other settings and to other patient populations.	Q1-A
Examine effect of systematically implementing an AD in nursing homes on patient & family satisfaction with involvement in decision making & on health care costs (Molloy, Guyatt et al. 2000).	RCT, validated questionnaires with nursing home residents (n=1292), matching groups	Systematic implementation of a program to increase use of ADs reduce health care services utilisation without affecting satisfaction with care or mortality.	Systematic application of AD will increase the need for effective palliative care in nursing homes.	Q1-A
Overview of how Respecting Choices Program works and how it evolved (Hammes 2003).	Expert Opinion	Outlines core elements: Focus on continuous improvement, embedded ACP in larger routines, Create effective monitoring tools, sustain financial and institutional support, training	Most intractable obstacles are the lack of dedicated resources and lack of commitment of changing health care routines.	Q2-B
Exploration of challenges & success of planning coalition 'Life Planning 2000' in Wisconsin (Marchand, Fowler et al. 2006).	Qualitative Study (n=24)	Major themes: commitment, leadership & funding; cohesiveness, working towards a common goal; and outcomes including educational tool development. Need for evaluation process, resources must be commensurate with goals.	Strong leadership, paid staff, adequate funding, and the collaboration of diverse groups working towards a common goal are essential if a coalition promoting EOL care planning is to be successful.	Q2-B
Examine EOL experience of elderly deceased dying out of hospital & their family care givers in a state in which most Medicare deaths occur in community settings (Tilden, Tolle et al. 2004).	Random sample of family care givers (n=1189)	Despite high rates of ADs & hospice enrolment, perceived symptom distress was high for a subset of deceased. (some preventable symptoms). This profile of distress is partially avoidable with early & aggressive palliation. Caregiver strain was common.	As location of death shifts from hospital to community, unmet deceased and family needs require new clinical skills and healthcare policies.	Q1-B

SPECIFIC AIM	SAMPLE POPULATION	RESULTS	IMPLICATIONS	QUALITY
Describes the development of FOOTPRINTS, an ACP program for children (Toce and Collins 2003).	Expert Opinion	The FOOTPRINTS program has been developed as 'best practice' model for paediatric EOL care. Challenges encountered: societal norms, insufficient staffing, inadequate research and evaluation support.		Q2-B
Describes the 'Do It Your Way' program, a demonstration project on EOL care for persons with serious mental illness (Foti 2003).	Expert Opinion + evaluation	'Do it you way' draws attention to the right of persons with serious mental illness to participate in ACP and to access quality EOL care. The project was successful in some measure. Project implementation was hindered by institutional setting. Most meaningful component was working collaboratively with patients.	Conversations about EOL care can occur without fear that a person's psychiatric symptoms or related vulnerabilities will undermine the process.	Q2-B
Describes incremental gains toward improving ACP for EOL care (Tolle and Tilden 2002).	Expert Opinion	Action strategies have required data gathering and reporting, and coalition building with a focus on system change. Public education through the news media has proved to be a vital component of Oregon's process of change.	Need to focus on minority groups that are not reached by current program.	Q2-B
Basic outline of key ingredients of Respecting Choices Program (Hammes 1999).	Expert Opinion	Key ingredients of success: Values discussion, Key opinion makers, process focus, training of staff, management of program, sustainability, quality improvement, community involvement & administrative support.	ACP focus should be on relationships rather than abstract values.	Q2-B

SPECIFIC AIM	SAMPLE POPULATION	RESULTS	IMPLICATIONS	QUALITY
Offers practically oriented set of core steps and skills based on clinical experience and on research (Emanuel, Danis et al. 1995).	Expert Opinion	ACP components include: Introducing topic & giving information. Facilitating the discussion. Completing ADs and record statements. Reviewing and up-dating directives Applying directives to circumstances.	Focus on ongoing relationship between patients and health providers.	Q2-C
Determine for geographically defined population prevalence & type of EOL planning & the relationship between EOL plans & decisions (Hammes and Rooney 1998).	Retrospective Chart Review (n=540)	ACP can be prevalent & effectively guide EOL decisions.	Confirms the success of La Crosse project but does not allow for transferability of findings.	Q1-C
<b><i>15. System-Wide Approach Communication &amp; Decision Making</i></b>				
To produce an ACP communication tool that addresses the differentiated needs of patients on various illness trajectories (Briggs 2004).	Qualitative pilot study: 27 patient-surrogate pairs	Description and validation of rationale for using an in-depth interview to build and strengthen relationships.	Importance of experienced facilitators able to broach a broad range of topics ranging from illness trajectory and treatment options to breaking bad news. In depth interview valuable tool to initiate ACP process.	Q2-A
Discusses a composite case study in a nursing home setting, which builds on experience with multi-site collaborative efforts and introduces quality improvement methods in the context of EOL care (Lynn, Nolan et al. 2002).	Case Study/Expert Opinion	Quality improvement hinges on to Plan, Do, Study, and Act on new insights (the PSDA cycle). Repeated PSDA cycles generate deep understanding of complex systems and make sustainable improvements rapidly.	Demonstrates need to implement a quality improvement system based on measured outcomes.	Q2-A
To improve an existing ACP intervention by developing a communication tool to lower barriers to ACP discussions (Schwartz, Lennes et al. 2003).	Qualitative Study (n=52) with terminally ill patients.	Streamlining of 10 question interview tool – The Living Well Interview. Result indicate two-tailed response defaulting in either generativity or essence.	Living Well Interview is an effective ACP communication tool.	Q2-A Q1-B

SPECIFIC AIM	SAMPLE POPULATION	RESULTS	IMPLICATIONS	QUALITY
To assess the feasibility of a patient-centred ACP (PC-ACP) approach to patients with chronic illnesses and their surrogates with respect to promotion of shared decision-making outcomes – congruence between patient and surrogate, patient’s decisional conflict, and knowledge of ACP (Briggs, Kirchhoff et al. 2004).	Experimental trial (n=27) patient-surrogate pairs (1 control, 1 intervention)	Higher patient-surrogate congruence, greater satisfaction with decision-making process, and less decisional conflict was recorded in the intervention group.	The PC-ACP interview can be effective in promoting shared decision-making between patients and surrogates and in producing greater satisfaction with the process of decision-making and less decisional conflict.	Q1-B
To evaluate short-term effects of PC-ACP (Song, Kirchhoff et al. 2005).	RCT, 32 dyads of patients undergoing surgery & their surrogates, random assignment	PC-ACP significantly improved patient-surrogate congruence and reduced patients’ decisional conflict. Anxiety and ACP knowledge did not differ between groups.	PC-ACP can be an effective approach to ACP. It hinges on its specificity and relevance to patients’ medical condition.	Q1-B
Reinterprets findings of Hines & Ditto about the possibility of effective proxy decision-making (Hammes 2001).	Expert Opinion	Their findings that self-directed ADs generally fail to give adequate information to proxy to understand EOL wishes of patient is re-interpreted.	A coordinated, ongoing value-extrapolating communication strategy is needed	Q2-B
Describes evaluation of short-term clinical utility of early ACP (Schwartz, Wheeler et al. 2002).	Randomised Trial (n=61), 1 control 1 intervention group	A facilitated discussion about EOL care between patients and their health care agents helps define and document the patient’s wishes for both patients and agent.	Confirms the findings of the Respecting Choices team.	Q1-B
<b>16. System-Wide Approach – EOL quality Tool</b>				
Examine psychometric properties of the Decisional Conflict Scale (DCS) when used as a measure of patients’ evaluation of their EOL decision-making process (Song and Sereika 2006).	Two independent samples. (n=59). Control-intervention.	DCS is a viable research instrument for measuring quality of EOL decision-making. However, uncertainty subscale showed a weak discriminating ability & lack of association with the other two subscales, the modifiable factors contributing to uncertainty & the effectiveness of decision-making.		Q1-B

SPECIFIC AIM	SAMPLE POPULATION	RESULTS	IMPLICATIONS	QUALITY
<b>17. System-Wide Approach – Pathways of Care</b>				
Determine whether a goal-based system of ACP, which allows patients to choose among five 'pathways of care' enables physicians to select treatment options in specific clinical situations (Bercovitch and Gillick 2002).	Pencil-paper test involving physicians (n=19) and nurses (n=3).	High concordance with reference answers.	Establishing pathways of care by getting nursing home residents to prioritise goals of care may assist clinicians to narrow the range of suitable options when faced with an acute medical problem.	Q1-C
Explores factors that may contribute to sub-optimal care for patients dying in hospital (Edmonds and Rogers 2003).	Review	Strategies to improve care such as the use of integrated care pathways, ADs, and education initiatives are discussed.	Need for improvement of care in dying patients possibly by the use of integrated care pathways, ADs & education initiatives.	Q1-C
<b>18. System-Wide Approach – Administrative Processes</b>				
Evaluation of POLST tool (Meyers, Moore et al. 2004).	Chart Review (n=21) convenience sample of nursing home residents.	POLST form was in use and found promising.	POLST form useful ACP tool to record patient preferences.	Q1-C
Assess use of POLST & identify patterns of orders documented on residents' POLST form (Hickman, Tolle et al. 2004).	146 nursing facilities – phone survey (n=356) with nursing home residents, POLST form review.	The POLST form is widely used in Oregon nursing homes.	POLST can be used to transform patient wishes into medical orders.	Q1-C
Evaluate whether terminal care was consistent with POLST (Lee, Brummel-Smith et al. 2000).	Retrospective Chart Review (n=58)	POLST is effective to limit the use of some life-sustaining interventions; factors that lead to deviation by physicians of patients' stated preferences require further exploration.	POLST shows promise as a tool for ensuring patient preferences regarding EOL care are carried out.	Q1-C
Examine extent to which (POLST) form ensured that nursing home residents' wishes were honoured for DNR & requests for transfer only if comfort measures fail (Tolle, Tilden et al. 1998).	Prospective using chart data (n=180) nursing home residents with POLST, DNR, & wanted transfer only if comfort measures failed.	POLST orders regarding CPR in nursing home residents were universally respected. Subjects received remarkably high levels of comfort care & low rates of aggressive life-extending treatment	POLST effectively limits aggressive treatment.	Q1-C



SPECIFIC AIM	SAMPLE POPULATION	RESULTS	IMPLICATIONS	QUALITY
<p>Evaluate emergency medical technicians (EMTs) experience with the physician orders for life-sustaining treatment (POLST) program &amp; learning about attitudes regarding its effectiveness (Schmidt, Hickman et al. 2004).</p>	<p>Anonymous mailed survey to stratified random sample (n=1048)</p>	<p>Most respondents have experience with the POLST program. EMTs find the POLST form useful: 75% that it provides clear instructions about patient preferences, 93% that it is useful in determining treatment in care of cardio-pulmonary arrest, 63% that it is useful when the patient has pulse &amp; is breathing.</p>	<p>POLST form is useful.</p>	<p>Q1-C</p>

## 3. The State of the Science

The central theme in the literature on ACP is the emergence of an expert opinion-led consensus. A growing number of experts in the field recognise the need to treat ACP as a system-wide process. Whereas earlier studies featured approaches geared to increase Advance Directive (AD) completion rates, principally by encouraging AD discussions between patients and health practitioners, more recent studies advocate a multi-pronged strategy based on

- an ongoing values-directed discussion involving health professionals, clients, and family,
- a transformation of systemic processes to support ACP across a range of institutional settings,
- the insertion of ACP into clinical practice and culture, and
- the involvement of communities and the wider public.

Two events have contributed to the emergence of this consensus: The challenges to ACP evident in the SUPPORT and the remarkable success of the Respecting Choices® program in La Crosse, Wisconsin.

### 3.1. Issues around the SUPPORT study

At the time of the passing of the Patient Self-Determination Act (PSDA) in 1991 there was an implicit expectation that the new legislation would lead to changes in end of life (EOL) care. However, although the prevalence of Advanced Directives (AD)s rose significantly over the course of the following years, the overall AD completion and compliance rates remained low (Teno, Lynn et al. 1994; Teno, Branco et al. 1997; Yang, Bentrem et al. 2004). This prompted authors such as Joan Teno to call for an explicit focus on the functionality of ADs rather than AD completion rates. Concurrently, it emerged that Advance Care Planning (ACP) discussions between seriously ill patients and physicians were not stimulated by the presence of ADs alone (Virmani, Schneiderman et al. 1994; Teno, Lynn et al. 1997). With this in mind, many authors implicitly or explicitly began to embrace a more integrated approach to ACP.

The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) intervention was one of the first major studies to address ACP in a more integrated fashion. It primarily sought to stimulate AD discussions between patients and health professionals by making use of nurse facilitators who conducted patient/family interviews and provided physicians with prognosis models as well as written instructions about patient/family preferences regarding EOL care.

As is widely known, the SUPPORT intervention did not achieve its aim. The intervention did not enhance patient-physician communication nor did it significantly impact on medical decision-making at the end of life (Teno, Lynn et al. 1997; Teno, Licks et al. 1997).

However, it clearly evidenced

- a lack of communication regarding EOL care between patients/families and health professionals,
- a potential over-utilisation of aggressive life-sustaining treatments, and
- a potential under-treatment of distressing symptoms (pain, dyspnea, or confusion) at the end of life (Covinsky, Fuller et al. 2000).

Moreover, the SUPPORT study generated a number of re-analyses of the original data. A systematic review summarises the implications that could be inferred from these studies in the following manner:

- It is a difficult and complex task to change deeply entrenched patterns of EOL care,
- Health providers need to help patients and family members to understand illness trajectories and treatment choices,
- Health providers should initiate ACP discussions,
- Screening for depression in seriously ill patients may allow for appropriate treatments and enhanced ACP decision-making,
- A realistic counselling regarding probable outcomes of treatment choices may help patients/families to make decisions,
- Administrative measures are needed to diminish variability in EOL care,
- Given the incongruence of patients and surrogate preferences, it is important to have a patients' own reported perception of values and preferences,
- Nurses could play a role in assessing patients for unmet ACP needs and check for incongruity between patients and physicians regarding treatment choices, and
- Health providers need to ask specific questions about patient preference for treatments that are relevant to the patient's condition (Rutledge, Donaldson et al. 2001).

Furthermore, research conducted in Europe supports the findings that issued from the Support study and suggests the need for a more systemic approach to the implementation of ACP. For instance, a cross-sectional study comparing the attitudes of German and Swedish physicians and nurses indicates that a relatively high number of health professionals would act against patients' wishes regarding EOL care. The same study also demonstrates that

increased amounts of information about patients' treatment choices tends to increase compliance (Richter, Eisemann et al. 2002). In the aftermath of the SUPPORT study, some of the study's original authors questioned the validity of the shared decision making model that underpinned the SUPPORT study and raised the need to focus on improving pattern of practice through better communication and more comprehensive, system-level innovations and quality improvement (Teno, Lynn et al. 1997; Lynn, Arkes et al. 2000). Hence, whereas the SUPPORT study did not fulfil the expectations originally vested in it, it fundamentally changed the outlook of experts in the field of ACP.

### **3.2. Sub-fields in literature on ACP models**

Although the SUPPORT study provided a rough sketch of the processes, cultures, and attitudes that might undermine attempts to implement ACP, it left many important gaps in the emergent knowledge base of ACP. Key hypotheses regarding the causal connections of variables remained untested. As a result, many researchers set out to examine the core assumptions generated by SUPPORT study and to shed light on the factors that formed barriers in the way to a more comprehensive ACP. From the mid 1990s onward, such research efforts led to the formation of sub-fields within the literature on ACP. The following paragraphs provide an overview of the most significant research conducted within these sub-fields dealing with (1) communication, (2) education, (3) decision making, and (4) administrative processes.

#### **Communication:**

Research focusing on the barriers to ACP suggested that the single most important factor associated with patients' failure to complete ADs was the omission of physicians to discuss ACP (Ali 1999). Moreover, research demonstrated that chronically ill patients were more satisfied with their primary care physicians and the care they deliver when ADs were being discussed (Tierney, Dexter et al. 2001). With this in mind, researchers began to analyse the quality of patient-physician ACP communication. Already earlier research had suggested that physicians often held (1) erroneous views about the inappropriateness of ADs, (2) experienced time as well as emotional barriers, and (3) did not have sufficient knowledge to effectively discuss ADs (Morrison, Morrison et al. 1994). Moreover, there appeared to be a substantial gap between what patients wanted to discuss and what they were discussing with their physicians (Chambers, Diamond et al. 1994). In a seminal study, Tulskey, Fischer et al. brought to light the predominantly poor quality of ACP discussions between patients and physicians and offered a communication schedule to improve ACP communication (1998).

Other research has focused on the ability of medical residents to discuss ADs has shown that didactic education interventions often fail to produce competent ACP facilitators and that many residents who consider themselves competent to discuss ADs with patients fail to engage in recommended behaviour for such discussions (Buss, Alexander et al. 2005). This questions the validity and effectiveness of education modules designed during the mid 1990s

such as described by McCann, Chodosk et al. (1998). Bearing such education shortcomings in mind, a tool to assess knowledge and ability to address basic EOL issues was devised (Aronson and Kirby 2002). Research evaluating the capacity of social workers to discuss ADs has been more favourable (Black 2004; Black 2005).

## **Education**

Studies focusing on ACP education predominantly describe and/or evaluate the impact of education strategies to promote the completion of ADs. This question has received much attention as education interventions are regarded as a central aspect of ACP promotion. Indeed, research has shown that a lack of knowledge and understanding of ADs in conjunction with factors such as the additional time and paperwork requirements associated with the completion of ADs as well as legal implications tend to undermine ACP efforts (Gates, Schins et al. 1996).

One of the key questions that surfaced in the literature on ACP education was the question whether simple education interventions can increase AD completion rates. A systematic meta-analysis of nine random control trials suggests that simple patient-centred interventions may indeed increase AD completion rates (Patel, Sinuff et al. 2004). Although several subsequent studies not included in this meta-analysis tend to support the findings of Patel and Sinuff's et al., there is evidence from studies that report mixed results of educational and motivational interventions that the causal link between simple education interventions and AD completion rates might be more complex (Sulmasy, Song et al. 1996; Cugliari, Sobal et al. 1999; Pearlman, Starks et al. 2005).

Research focusing on multi-faceted education interventions revealed some of these complexities. Whereas authors were able to demonstrate that education interventions focused on health professionals and/or potential clients can increase the discussion and documentation of ADs (Molloy, Russo et al. 2000; DeLaGarza, Andersen et al. 2001), it also emerged that such discussions frequently lacked the clarity and detail required by families and health professionals in order to honour patients' preferences (McDonald, Deloge et al. 2003). Moreover, research conducted with HIV/AIDS patients revealed that while EOL treatment discussions may increase the rate of AD completion, ADs are often legally invalid (Ho, Thiel et al. 2000). Nevertheless, research conducted within in a nursing home setting demonstrated that educational interventions aimed at health professionals can significantly improve the quality of EOL care (Keay, Alexander et al. 2003).

Searching for alternative avenues to promote ADs within a hospital setting, research suggested that the pre-operative evaluation period can be an opportunity to encourage patient and proxy communication about EOL care (Grimaldo, Wiener-Kronish et al. 2001) confirming the importance of incorporating ACP into the professional practice that precedes surgery (Yang, Bentrem et al. 2004). A small number of studies have focused on the impact that the provision of ACP information leaflets might have on the comprehension and

completion of ADs within a hospital context. For instance, research has demonstrated that hospitals that provided the AD forms in advance of the day of admission had significantly higher AD completion rates than hospitals that did not (Cugliari, Miller et al. 1995). Focusing on an ICU context Azoulay, Pochard et al. have demonstrated that a standard family information leaflet significantly improved satisfaction and comprehension of information provided to family members of ICU patients (Azoulay, Pochard et al. 2002).

Focusing on education methodology several studies highlight that group education intervention is an effective tool for facilitating completion of ADs, especially among older patients (Dipko, Xavier et al. 2003; Gutheil and Heyman 2005). Moreover, a recent action research-inspired study demonstrated the usefulness of a peer education intervention in overcoming obstacles customarily encountered by top-down approaches (Sanders, Seymour et al. 2006).

Key points in the literature evaluating education interventions include the need for

- ongoing evaluation,
- continuous improvements (Keay, Alexander et al. 2003),
- staff education so that health professionals have the necessary skills to conduct EOL discussions, and
- making time to encourage patients to share their EOL choices (Gutheil and Heyman 2005).

## **Decision-Making**

Much of the ACP debate focuses on issues around the capacity of individuals to make meaningful ACP decisions. For instance, a recent study demonstrated that although nursing home residents might be able to articulate their treatment choices, their ability to fully comprehend the consequences of such choices might be limited. These findings led the authors to call for clinically meaningful cut-off scores (Allen, DeLaine et al. 2003). Research focusing on Alzheimer's patients revealed that dementia can trigger bias on the part of health professionals that pre-determines the way ACP is being handled. A study illustrated that physicians do not adequately address ADs with such patients and their care givers as the diagnosis is often erroneously equated with a lack of decision-making capacity (Cavalieri, Latif et al. 2002). In fact, questions around the capacity of individuals with dementia to make EOL treatment decisions have informed earlier research and have led to the development and validation of screening instruments and assessment reference standards (Molloy, Silberfeld et al. 1996; Fazel, Hope et al. 1999). However, whereas it is claimed that such tools and instruments are able to differentiate whether patients are capable to make ACP decisions, it has also been argued that the cut-off scores for patients' capacity to appoint proxies ought to

be lower than for recording EOL treatment decisions, for instance (Mezey, Mitty et al. 2000). Moreover, reviewing the literature focusing on dementia and ACP, Mezey, Mitty et al. have argued that dementia often has no clear markers and that it presents no clear evidence of recurrence (Mezey, Mitty et al. 2000). Because the changes are subtle, they often fail to trigger the perception of need for advance directives. Furthermore, recidivation in conjunction with variability and the confounding influence of medication turns competency assessments into a more complex task than often assumed by authors. The ambiguities that underpin ACP for dementia patients highlight the importance of initiating ACP discussions earlier. Indeed, research has demonstrated that ACP conducted earlier (not immediately prior to death) produces a more effective outcome for the cognitively impaired (Cohen-Mansfield and Lipson 2003-2004).

Studies exploring ACP treatment preferences explore factors that influence choices, analyse the decisional congruence of patients and their surrogates, and investigate how adults communicate their EOL wishes. Pfeifer, Mitchell et al. demonstrated that for patients with chronic lung disease, severity of disease and intensity of recent care are not associated with patients' desire or readiness for EOL discussions (Pfeifer, Mitchell et al. 2003). Thus, actual illness severity measures cannot be used to establish the readiness of seriously ill people to discuss ACP. The authors suggested that it might be desirable to have ACP discussions at an earlier point on a patient's illness trajectory. Focusing on how actual and perceived illness trajectories influence EOL treatment preferences, a recent study suggested that treatment preferences in seriously ill older patients are shaped by four factors: treatment burden and treatment outcome, variability in the assessment of treatment burden, uncertainty, and shifting valuations of treatment outcomes (Fried and Bradley 2003). Another study demonstrated that the onset of a serious illness appears to affect actual treatment decisions so that they at times no longer correspond to preferences recorded in ADs. Moreover, the same study suggested that surrogates preferences correlate poorly with patients' stated treatment preferences (Lee, Smith et al. 1998). Thus, patient preferences are shaped by the perceived and actual illness trajectory and tend to be less stable than had been suggested earlier.

More recently, authors have developed and/or validated an increasing range of tools including a tool that assess the readiness of patients to discuss ACP (Calvin and Eriksen 2006), a tool to assess the willingness of surrogates to communicate ACP decisions on behalf of a patient (Buckey and Abell 2004), and an instrument to measure three distinct factors which people consider important to a 'good death' (Schwartz, Mazor et al. 2003).

## **Administrative Processes**

The sub-field of administrative processes in ACP focuses predominantly on the way patients' EOL treatment preferences are made available throughout the health care system, to what degree policies and guidelines regulate ACP processes, and whether ACP impacts on EOL care. Research focusing on the translation of patients' EOL treatment decisions into medical

orders clearly outlined the need to improve the availability and quality of patients' EOL treatment preferences in medical charts. Studies focusing on administrative processes in hospitals showed that EOL treatment preference documents were often not available or visible to persons involved in the care of seriously ill and/or dying patients (Badzek, Leslie et al. 1998). Furthermore, research demonstrated that the labelling system used by hospitals was highly inaccurate and that health professionals often failed to correctly follow or understand the intended labelling process (Wallace and Desbiens 2004). Nevertheless, research also showed that relatively small interventions such as a simple chart reminder had the capacity to promote ACP discussions and increase the completion rate of ADs in patients with AIDS (Walker, Mandell et al. 1999).

Research conducted in nursing homes contributed greatly to a more differentiated understanding of the issues connected to documentation and policy. It was found that although institutional forms were widely used in an effort to promote the legal requisites of the PSDA, researchers cautioned that such forms were used instead of ADs and a more comprehensive ACP discussion involving health professionals, residents, and families (Bradley, Blechner et al. 1997). Also, it was found that ACP efforts often dichotomised and, thus, over-simplified EOL treatment choices. As a result, hospice services were underutilised and palliative care services were inconsistent with accepted standards (Happ, Capezuti et al. 2002). The lack of rigorous AD and palliative care policies leading to unwanted treatment within nursing homes was raised by studies focusing on the U.S. as well as the Australian context (Dobalian 2004; Brown, Grbich et al. 2005). Moreover, insights that ACP is often not decisive in determining treatment choices led some researchers to question the process per se, raising the possibility that, in light of the psycho-social tensions caused by the process, an alternative to ACP could prove more appropriate (Anderson, Sikorski et al. 2006).

Research focusing on the effectiveness of ADs within an ICU context concluded that ADs had little impact on decisions to initiate life-supporting treatment and that ADs are more likely to guide medical decisions at an earlier point, before or during a patient's hospitalisation (Wallace, Martin et al. 2001).

Succinctly summarising research and practice-based insights focusing on systemic issues, Lynn and Goldstein outlined some of the basic mistakes frequently made in EOL care that lead to unwanted treatment. The authors make the following recommendations:

- Enrolling in or leaving any program of care should routinely lead to reviewing and documenting ACP. Facilities should audit rates and work toward 100% completion and transfer of plans. Medicare and other payers could compensate at a higher level those institutions that achieved this goal.
- Patients living with eventually fatal chronic illness should have a care team that stays with them through all settings. Facility-based clinicians can play important



roles, but the continuity clinicians must remain involved since they know the patient, family, and living arrangements across time.

- Direct care staff that the family comes to know and trust should continue through difficult times, rather than switching with every change in payer.
- Documented plans should be available and understood across settings.
- Emergency care providers should regularly ask about ACP when serving very sick patients at home or in nursing facilities (2003).

In order to help health professionals to develop better strategies to lower barriers to AD implementation, Stiller, Molloy et al. developed an instrument to reliably measure barrier to AD implementation in different health care settings (2001).

### **4.3. System-Wide approaches**

Although many interventions that incorporated a system-wide approach were piloted during the 1980s, corresponding research, such as conducted by Emanuel, Danis et al. (1995), was only published from the mid 1990s onwards. One of the earliest and most successful system-wide ACP approaches is the Respecting Choices (RC) program®, developed by the La Crosse Area Medical Centers' Task Force on Advance Directives in Wisconsin. Implemented in 1991, the RC program developed out of a pilot study conducted during the second half of the 1980s.

Key features of the Respecting Choices program are

- ongoing values discussions,
- to embed ACP in larger systems,
- ongoing support of key opinion makers,
- sustained financial and institutional support,
- process focus,
- extensive staff training,
- program management,
- sustainability,
- effective monitoring tools,
- quality improvement, and
- community involvement. (Hammes 1999; Hammes 2003).

A review of medical charts clearly documented the success of the Respecting Choices (RC) program in La Crosse. An assessment of the impact of the RC program conducted between 1995 and 1996 revealed that around 85% of deceased people during that period had ADs and 95% of these ADs were attached to medical record (Hammes and Rooney 1998). However, while this study clearly suggests that ACP can significantly boost AD completion rates and can effectively guide EOL treatment decisions, we know very little about the salience of

individual program elements. In other words, practitioners have demonstrated that the system-wide approach can work, there are only very few studies that illustrate why it works. The following paragraph provides an overview over the mainly qualitative research that establishes causal connections between individual program elements and the positive outcome of interventions.

## **Evaluation of System-Wide Programs**

A recent qualitative study explored the factors that led to the success of the planning coalition that developed 'Life Planning 2000', an initiative based on the La Crosse RC model that was introduced to the whole of Wisconsin. Major themes that surfaced in the study were a common vision, cooperation, leadership, adequate funding, paid support staff, meeting education needs, as well as an ongoing evaluation process (Marchand, Fowler et al. 2006). The importance of a comprehensive evaluation process tied to continuous improvement has also been fore-grounded by a group of researchers associated with Joanne Lynn (2002). Another study focusing on incremental gains toward improving ACP in Oregon drew attention to the importance of coalition building. Moreover, in addition to the importance of strong coalitions, evaluation and reporting strategies in conjunction with public education programs through the new media proved valuable in terms of forming the necessary thrust for system-wide change (Tolle and Tilden 2002). Nevertheless, despite the program's success, researchers alerted to the fact that minority groups had not been reached by the program. In a subsequent study, Tilden and Tolle documented unmet needs as a result of an increasing shift in the location of death from hospital to community. The study found a high level of symptom distress in a subset of the deceased, requiring new clinical skills and healthcare policies (Tilden, Tolle et al. 2004).

## **Other System-Wide Initiatives & Key Researchers**

Other programs that have been developed within a system-wide framework include the 'Do It Your Way' program, an intervention geared to facilitate EOL treatment decision-making for the seriously mentally ill (Foti 2003); 'FOOTPRINTS', an ACP program for children (Toce and Collins 2003); as well as other programs aimed at nursing home residents (Molloy, Guyatt et al. 2000; Morrison, Chichin et al. 2005). Among the barriers encountered by the program staff of these projects were lack of institutional support (Foti 2003) as well as societal norms, insufficient staffing, and inadequate research and evaluation support (Toce and Collins 2003).

Key researchers and practitioners currently associated with system-wide approaches are

- Hammes, Briggs (Gundersen Lutheran Medical Foundation, La Crosse)
- Lynn, (Centre for Palliative Care Studies, Washington)
- Teno (George Washington University, Washington)
- Molloy (Ontario)
- Singer (Toronto)

- Tolle, Tilden, Hickman (Oregon)
- Sanders, Seymour (UK)
- Schwartz (University of Massachusetts)
- Tulsky (Duke University, Durham), and
- A group of researchers associated with the University of Wisconsin.

## **Communication & Decision-Making**

One of the areas that has received significant attention within the literature focusing on system-wide approaches is that of patient/family – health professional communication. Point of departure for this nascent debate was the various deficiencies identified by the above-mentioned research. RC practitioners such as Hammes argue that a coordinated, ongoing value-extrapolating communication process is able to produce much more fruitful ACP discussions (2001). Indeed, the effectiveness of facilitated discussions about EOL care between patients and their health professionals in terms of defining and documenting patients' wishes for both patients and surrogates have been confirmed by a randomised controlled trial (Schwartz, Wheeler et al. 2002). Building on these insights, practitioners have developed a range of differentiated communication tools geared to foster a meaningful, value-based ACP discussion. For instance, Carolyn Schwartz, Inga Lennes, Bud Hammes, and others developed a communication tool based on qualitative analysis: the 'Living Well Interview' (2003). This interview, according to the authors, allows physicians to explore and become aware of a patient's values so that future EOL decisions can incorporate those values. Taking issue with the notion that more and a better understanding of information provided to patients automatically leads to better EOL treatment decisions, the authors argued that patients become easily subsumed into a culture of medical decision-making that focuses on treatment rather than on life experience, quality of life, and new meaning. The authors stress the importance of focusing on acceptable health states and on valued life activities and to include family members into the ACP discussion so as to create the possibility for a value consensus among the different parties. The study rejects the medicalisation of ACP arguing that medicalisation reinforces communication barriers that can be lowered with the help of an open-ended discussion utilising the 'living well interview'.

Similarly, Linda Briggs designed a patient-centred, in-depth interview with seriously ill patients and their surrogates to build and strengthen relationships (2004). Based on the insight that the communication needs of people on different illness trajectories are different, Briggs' approach hinges on the role of experienced facilitators able to inform patients about illness trajectories, treatment options, as well as likely outcomes. The approach builds on a representational strategy to health information involving the following five stages: representational assessment, exploring misconceptions, creating conditions for change, introducing replacement information, and summarising the discussion. Briggs' qualitative study suggests that patients find it often easier to open up to strangers than to talk to their loved ones and underscores the importance of listening. Subsequent research work assessed

the feasibility and validity of a further variant of patient-centred decision making: Patient-Centred Advance Care Planning (PC-ACP). The PC-ACP approach combines the Living Well Interview with two recent decision-making models (interactive and representational) and also incorporates several well-known tools such as the Decisional Conflict Scale. The study concluded that PC-ACP can promote shared decision-making between seriously ill patients and surrogates, is able to reduce decisional conflict, and is particularly sensitive to patients' medical condition (Briggs, Kirchhoff et al. 2004; Song, Kirchhoff et al. 2005).

More recently, Song and Sereika have examined the psychometric properties of the 'Decisional Conflict Scale' (DCS) when used as a measure of patients' evaluation of their EOL decision-making process concluding that the DCS may be a viable research instrument for measuring the quality of EOL decision-making (2006).

A slightly different line of research has explored the usefulness of a goal-based approach to ACP allowing patients to choose among different 'pathways of care'. An exploratory study based on a small sample size suggests that within a nursing home context establishing pathways of care and prioritising pre-defined goals of care may assist clinicians to narrow the range of suitable options when faced with an acute medical problem (Bercovitch and Gillick 2002). This approach resonates with Lynn and Goldstein's 'useful care plan' (2003).

## **Administrative processes**

Another area of study that has attracted the attention of researchers focusing on system-wide approaches is that of making patients' EOL treatment choices more readily available to health professionals. As mentioned above, patients' EOL treatment choices are often not recorded in the medical chart, are difficult to access, or are overlooked by health professionals. The 'Physicians Order for Life Sustaining Treatment' (POLST), has been developed to effectively translate patients' EOL wishes into a formal statement recorded in the medical charts. Several studies evaluate the effectiveness of the POLST tool to facilitate EOL decision-making. Within a nursing home context, the POLST has been found to be widely used in Oregon (Hickman, Tolle et al. 2004), to transform patient wishes into medical orders (Hickman, Tolle et al. 2004; Meyers, Moore et al. 2004), and to be effective for limiting the use of some life-sustaining interventions (Tolle, Tilden et al. 1998; Lee, Brummel-Smith et al. 2000). A recent survey focusing on the usefulness of the POLST found that most respondents had seen the POLST in use, that it provides clear instructions about patient preferences, that it is useful in determining treatment in case of cardio-pulmonary arrest and that it is useful when the patient has pulse and is breathing (Schmidt, Hickman et al. 2004). Numerous issues, such as the factors that lead to deviation by physicians of patients' stated preferences, require further exploration.

## **Strength of Evidence:**

The following pages summarises the key implications for health professionals based on this review. No generally accepted guidelines to grading evidence or recommendations has emerged to date (Sackett 1986; Woolf, Battista et al. 1990; Cook, Guyatt et al. 1992).

Formal guidelines hierarchically ordering 'levels of evidence' and 'grades of recommendations' were first popularized by the Canadian Task Force on the Periodic Health Examination (CTF) (Canadian Task Force on the Periodic Health Examination 1979). The CTF's recommendations were later revised in collaboration with the United States Preventive Services Task Force (USPSTF) (Jaeschke, Guyatt et al. 1994). Like previous attempts to classify 'levels of evidence', these guideline developers asserted that rigorous randomized trials produce the strongest evidence, and observational studies using cohort or case-control designs produce weaker evidence.

Because other determinants of the quality of evidence, such as sample size, recruitment bias, losses to follow-up, unmasked outcome assessment, atypical patient groups, un-reproducible interventions, impractical clinical settings, and other threats to internal and external validity were assessed at an earlier stage during the review process, strength of evidence is, at this stage, inferred from study design alone.

Since the CTF's taxonomy has been developed with systematic reviews of clinical trials in mind, it tends to exclude qualitative designs and is, as such, not appropriate for this review. As mentioned previously, due to substantial gaps in the research literature on ACP, this review incorporates qualitative research as well as study-based expert opinion. Although informed by the CTF guidelines, this review employs an extended taxonomy featuring both quantitative as well as qualitative research designs as developed by Rutledge, Donaldson et al. in their review of SUPPORT-inspired research (Rutledge, Donaldson et al. 2001). This has the advantage that recommendations made by these authors be incorporated in this review. In line with Rutledge, Donaldson et al., each practice implication is coded according to its strength of evidence. The matrix of the strength of evidence code is displayed in the following table (Table 4).

**Table 4: Strength of Evidence**

<b>A*</b>	Evidence obtained from 2 or more clinical trials.
<b>B*</b>	Evidence obtained from 1 clinical trial or 2 or more clinical research studies
<b>C*</b>	Evidence obtained form 1 methodologically sound study.
<b>D*</b>	Evidence obtained from research-based expert opinion.

\*Plus and minus signs (+/-) are added to these scores to differentiate between different levels of evidence within these categories. For instance, A+ stands for evidence obtained from 2 or more randomised controlled trials.

# Strength of Evidence & Key Implications

Key Implications For Practice	Evidence	Issues Of Clinical Significance
<b>1. Impact of ADs</b>		
ADs alone do not stimulate ACP discussions between seriously ill patients and physicians nor do they lead to ACP decision-making.	B+	Future work should focus on improving the current pattern of practice through better communication and more comprehensive ACP.
ADs can have little effect on decision-making about resuscitation.	B	Need to bear in mind the functionality of ADs and not only their completion rate.
There are striking variations between U.S. states regarding AD completion rates.	B	Need for uniform legislation, governmental action, and administrative measures may be required to address this variation.
<b>2. SUPPORT</b>		
A series of interventions - patient-specific prognostic modelling delivered to physicians for each study patient, nurse facilitators (NF) who communicated with study patients, families, and healthcare team members, and written instructions about patient/family preferences for treatment and care did not affect time spent in intensive care units, reports of pain severity; timing of DNR orders; accuracy of physician understanding of patients' desire for treatment; or cost of care.	A	It is difficult to change deeply entrenched patterns of EOL care. Need to focus on improving pattern of practice through better communication and more comprehensive, system-level innovations and quality improvements in routine care.
In general, congruence between physicians, family members, and patients regarding value of health and preferences for care do not exist automatically. The most reliable source for patient preferences is the patient.	A	Knowing patients' own reported perceptions of the value of his/her own health and preferences for care should be used rather than that of family members or physicians. Need to initiate ACP discussions earlier.

Key Implications For Practice	Evidence	Issues Of Clinical Significance
The dying trajectory varies across the serious illnesses requiring hospitalisation.	B	Health professionals need to help patients and family members understand potential trajectory of an illness and initiate/reinitiate discussions of potential decisions to be made during the illness.
When patients with serious illness approach the end of life, a preference for withholding life-sustaining measures such as resuscitation increases in likelihood.	B	It is up to health professionals to initiate discussions of life-sustaining measures making sure patients/family members understand the meaning of each measure and its likelihood of altering their length and quality of life.
Depression can confound patient preferences for care and may interfere with decision making in several domains	B	Assessment/screening for depression in seriously ill patients may allow for depression-alleviating treatment and enhance future decision making.
It is difficult to predict death for individual patients with most illnesses studied. Patients had a propensity to believe they would survive and this affected choices for treatment.	B	Need to create an ongoing ACP discussion early during an illness trajectory. Counselling regarding probable outcomes of treatment choices may help patients/family members make decisions.
Variability existed across hospitals as to whether patients died in the hospital or somewhere else, what treatments and diagnoses were used, when patients/families discussed resuscitation, and timing of hospital discharge	B	Administrative initiatives may be needed to diminish this variability and affect patterns.
A minority of seriously ill patients have advance directives; of those who do, only a small minority (>1/5) have directives that point to specific care preferences.	B	Health professionals need to ask specific questions about patient preference for treatments that correspond with patient's condition.
Family members asked to be patient 'surrogates' have great difficulty making certain decisions related to EOL, particularly when patients have not left ADs.	B	Health professionals need to spend time with family members who are trying to understand the patient's condition and its trajectory. New ways of helping family members and the health team facilitate decision making need to be tried.



Key Implications For Practice	Evidence	Issues Of Clinical Significance
When physicians are aware of, and especially when they agree with, patient preferences to forego life-sustaining treatment, fewer resources were used and healthcare costs decreased.	C	Nurses need to assess for incongruity between patients and physician regarding care/treatment preferences, facilitating discussions when appropriate, or coaching patients/physicians on how to engage the other in desired dialogue.
There is a substantial minority of seriously ill patients who have not discussed care/treatment preferences with their physicians and who desire such a discussion and whose need may go unmet.	C	Nurses need to assess patients for the 'unmet need' to discuss their care/treatment preferences with their physicians, and facilitate such discussions when appropriate.
<b>3. Patient-Health Professional Communication</b>		
Chronically ill patients (but not necessarily HIV/AIDS patients) are more satisfied with their primary care physicians and the care they deliver when ADs are discussed.	B	Need to discuss ACP with chronically ill patients. Need to conduct research focusing on whether ADs address the psychosocial and physical needs of patients on different illness trajectories.
The quality of such discussions is predominantly poor. There is a substantial gap between what patients wanted to discuss and what they were discussing with their physicians.	B	Need to improve ACP communication between patients and health professionals.
ADs often lack the clarity and detail required by families and health professionals in order to honour patients' preferences.	B	Need to improve the way ACP is being approached. Ongoing EOL care dialogue with health professionals, patients, and families might provide greater clarity and comfort about EOL preferences.
The single most important factor associated with elderly patients' (60+) failure to complete ADs was the omission of physicians to discuss ACP.	C	Need to stimulate physician-patient AD discussions. Geriatric nurses can use strategies to enable both physicians and patients to promote ADs. Need to promote ADs in wider community.
ADs are often legally invalid.	C	Government action needed to address the variance in legislation between states. Need to educate users and to provide the appropriate AD paper work.

Key Implications For Practice	Evidence	Issues Of Clinical Significance
In a nursing home context, education interventions focusing on health professionals can result in increased discussion and documentation of ADs.	B	Education of health professionals can increase AD completion rates.
In a nursing home context, education interventions focusing on health professionals can result in an improved quality of EOL care.	C	Education of health professionals can increase the quality of EOL care.
<b>4. Education Strategies</b>		
Simple education strategies may promote the completion of ADs.	A	Need to remember that such strategies must form part of a multifaceted approach targeting educational, systemic, as well as cultural barriers in the way of ACP.
Although education strategies may promote the completion of ADs, such interventions often yield mixed results.	A	Need to address the complexities underpinning ACP when designing education strategies.
Pre-operative ACP intervention significantly increased discussions between patients and their proxies.	B	The pre-operative evaluation period can be an opportunity to encourage patient and proxy communication about EOL care. Need to incorporate ACP into the professional practice that precedes surgery.
Whereas simple one-way, patient-focused communication interventions (eg. video tapes) may increase knowledge levels, they do not impact on AD completion rates.	B-	Need for a multifaceted communication intervention.
Important barriers to AD completion in U.S. home care agencies are: lack of knowledge or understanding of ADs, increased client admission time and/or paperwork, increased contact time with patient, and legal implications.	C	Need to educate home care agency staff. Provide the necessary administrative support so that barriers to AD completion are lowered.
<b>5. Education Methodologies</b>		
Group education intervention is an effective tool for facilitating completion of ADs, especially among older patients.	B	AD completion outcomes can be significantly improved through group intervention.

Key Implications For Practice	Evidence	Issues Of Clinical Significance
Participatory interventions featuring peer educators effectively increase the knowledge base of older people and can overcome obstacles encountered by top-down approaches.	B	Participatory action research in conjunction with peer educators can be an effective tool to devise ACP education material and to disseminate the message to older people.
Ongoing evaluation and continuous improvement are pivotal in education interventions.	B	Need to implement solid evaluation tools in conjunction with a continuous improvement process.
<b>6. Impact of Information Leaflets</b>		
Standard family information leaflets can significantly improve satisfaction with and comprehension of ACP information provided to families of ICU patients.	B	ICU care givers should consider issuing family information leaflets about ACP to improve the effectiveness of information they impart to family members.
Hospitals that provide AD forms in advance of the day of admission have significantly higher AD completion rates than hospitals that do not.	C	Hospitalisation can offer a valuable opportunity for patients to complete ADs.
<b>7. ACP Competency of Health Professionals</b>		
Lack of knowledge and erroneous beliefs about the appropriateness of ADs are the strongest and most consistent barriers to AD completion. Lack of time and discomfort also create important barriers.	B	Need to educate physicians about ADs, to feel comfortable with the topic, and how to approach the topic with patients.
Many medical residents consider themselves competent to discuss ADs with patients but fail to engage in recommended behaviour for such discussions	C	Didactics have less and potentially negative impact on EOL skills. Experiential learning correlates with behavioural and perceived competence.
Social Workers offer distinct skills in their AD communication practices and discuss ADs more frequently than either nurses or physicians.	C	Social workers are useful AD promoters in interdisciplinary health care team.

Key Implications For Practice	Evidence	Issues Of Clinical Significance
<b>8. Capacity Assessment</b>		
Health workers can make reproducible and valid assessments of patients' capacity to complete ADs. The SMMSE test accurately differentiates people who can learn about and ultimately complete ADs from those who cannot.	B	Short simple screening instruments can be applied to people with a range of intellectual abilities and can categorise the capacity to complete ADs. A rigorous assessment should be undertaken to establish capacity to complete ADs in other areas.
Development of a patient-centred approach for assessing competence to complete ADs that can successfully discriminate between normal and dementia patients.	C	Test can be used as a quick competence assessment tool valid in a variety of settings.
Evidence that while most residents retain their ability to state treatment preferences, many lack the capacity to understand treatment situations or appreciate consequences of treatment choices made. Resident capacity & global cognitive ability are not related to possession of ADs. Proxy religiosity, and resident social engagement are related to resident's possession of formal ADs.	C	Need for clinically meaningful cut-off scores for aspects of capacity particularly in less verbal individuals. Exploration of the potential impact of individual and proxy religiosity and/or spirituality on EOL medical decision making is also needed.
Physicians do not adequately address ADs with Alzheimer's patients and their care givers.	C-	Physicians need to be more knowledgeable & proactive in approaches to ACP with Alzheimer's patients.
<b>9. Preferences</b>		
EOL treatment preferences in seriously ill older people are shaped by four factors: treatment burden and treatment outcome, variability in the assessment of treatment burden, uncertainty, and shifting valuations of treatment outcomes.	C	A patient centred approach to ACP needs to incorporate a consideration of both treatment burdens and outcomes and the shifting perception of the likelihood of such outcomes. Patients' valuation of these outcomes may change over time.

Key Implications For Practice	Evidence	Issues Of Clinical Significance
<b>10. Timing of ACP discussions</b>		
After controlling for type of malignancy, reason for admission to ICU, severity of illness and age, the decision to initiate life-supporting interventions did not differ significantly among patients with and without ADs.	C	Within an ICU context, ADs have little impact on decisions to initiate life-supporting treatment. ADs are more likely to guide medical decisions at an earlier point, before or during a patient's hospitalisation.
Many deaths do not involve a decision making process immediately prior to death. Those that do differ from decision making processes in which death is not imminent.	C	EOL treatment decisions made earlier (not immediately prior to death) are more likely to lead to palliative care outcomes.
For patients with chronic lung disease, severity of disease and intensity of recent care are not associated with patients' desire or readiness for EOL discussions.	C	Physicians cannot use objective disease progression to predict which patients are most receptive to EOL discussions.
<b>11A. Medical Records in Hospitals</b>		
Physician chart reminders are effective for promoting discussion and completion of ADs in patients with AIDS although the effect is physician dependent.	B	Chart reminders can influence physician behaviour.
Documents outlining EOL treatment preferences are often not available or visible to or are overlooked by persons involved in the care of seriously ill and/or dying patients.	C	Need for EOL treatment preference documents to be available and prominently visible to all persons involved in the care of seriously ill and/or dying patients.
The labelling system used by hospitals to mark EOL treatment preferences is highly inaccurate and health professionals often fail to correctly follow or understand the intended labelling process.	C	Hospitals should include plans to check the accuracy of protocols when they are adopted to ensure that they are performing as intended.

Key Implications For Practice	Evidence	Issues Of Clinical Significance
<b>11B. Records in Nursing Homes</b>		
<p>Nursing homes are complying with the letter of the law by providing written information about ADs at the time of admission. Nursing homes frequently use institution-specific (locally designed) forms to document residents' treatment choices often to the detriment of more comprehensive ACP outcomes.</p>	<p>B+</p>	<p>Locally designed forms may promote ADs if they are offered in combination with in depth ACP communication.</p> <p>Although locally designed forms are often used in an effect to promote the legal prerequisites of the PSDA, such forms are used instead of ADs and a more comprehensive ACP discussion involving health professionals, nursing home residents, and family members.</p> <p>Need for education and rigorous policy initiatives in long-term care facilities to improve and facilitate individualised ACP and palliative care at EOL.</p>
<p>In general, nursing homes comply with DNH orders. However, some residents with DNH orders were hospitalised indicating the need for more rigorous policies.</p>	<p>B</p>	<p>Improved education regarding ADs, is necessary for health professionals and patients. More consistent and rigorous policies should be implemented in nursing facilities.</p>
<p>ACP discussions are often limited to cardiopulmonary resuscitation thus oversimplifying and erroneously dichotomising EOL treatment choices leaving especially palliative care alternatives for nursing home residents under-explained. Formal hospice services are under-utilised and palliative care efforts by nursing home staff were often inconsistent with accepted standards.</p>	<p>C</p>	<p>Need for education and rigorous policy initiatives in long-term care facilities to improve and facilitate individualised ACP and palliative care at EOL.</p>

Key Implications For Practice	Evidence	Issues Of Clinical Significance
<b>11C. Medical Records – Expert Recommendations</b>		
<p>Basic mistakes in EOL care are:</p> <ol style="list-style-type: none"> <li>1) Lack of planning and communication across institutional settings: Nursing home staff often fails to inform emergency staff or the hospital of a patient’s EOL treatment preferences.</li> <li>2) Inefficiency of ADs: ADs often fail to designate much more than a surrogate decision maker as actual treatment preferences are too vague to influence medical decision making. With advance care planning that specifies what is to happen with various likely complications, patient satisfaction increases and costs may decline.</li> <li>3) Need to make EOL treatment preferences available and visible in medical records.</li> <li>3) Lack of constant monitoring and revision of EOL preferences and actual status.</li> <li>4) Lack of continuity in the care for patients and families facing an EOL situation.</li> <li>5) Lack of evaluation and quality improvement strategies.</li> <li>6) Lack of financial incentives to promote excellence in EOL care.</li> </ol>	C+	<ul style="list-style-type: none"> <li>-Clinicians can make substantial gains by implementing quality improvement strategies within their organizations. Effective, appropriate advance care plans implemented across sites and time should be one quality indicator for judging care for vulnerable patients.</li> <li>-Need to use a more differentiated ‘pathway of care’ approach to ACP.</li> <li>-Enrolling in or leaving any program of care should routinely lead to reviewing and documenting ACP.</li> <li>-Facilities should audit rates and work toward 100% completion and transfer of plans. Medicare and other payers could compensate at a higher level those institutions that achieved this goal.</li> <li>-Patients living with eventually fatal chronic illness should have a care team that stays with them through all settings. Facility-based clinicians can play important roles, but the continuity clinicians must remain involved since they know the patient, family, and living arrangements across time.</li> <li>-Direct care staff that the family comes to know and trust should continue through difficult times, rather than switching with every change in payer.</li> <li>-Documented plans should be available and understood across settings.</li> <li>-Emergency care providers should regularly ask about ACP when serving very sick patients at home or in nursing facilities.</li> </ul>

Key Implications For Practice	Evidence	Issues Of Clinical Significance
<b>12. System Wide Approach – Effectiveness</b>		
Systematic implementation of a program to increase the use of ADs, reduces health care services utilisation without affecting satisfaction with care or mortality.	B	Systematic application of ADs will increase the need for effective palliative care in nursing homes.
Multi-component ACP intervention directed at nursing home workers significantly improved documentation and identification of patients' wishes regarding common life-sustaining treatments & resulted in higher concordance between patients' prior stated wishes and treatment received.	B	Multi-component ACP interventions can successfully raise AD completion and compliance rates. However, a larger study is required to determine whether these results are transferable to other settings and to other patient populations.
La Crosse RC system wide approach achieved an outcome where 85% of the deceased completed ADs and 95% of ADs were attached to medical records.	C	A system-wide approach as implemented in La Cross may raise completion and documentation rates. However, the transferability of the model has not been properly assessed.
The Oregon experience produced high levels of ADs and hospice enrolment. However, the perceived symptom distress was high for a subset of decedents. This profile of distress is partially avoidable with early and thorough palliation. Caregiver strain within this segment was common.	C	The system wide approach as implemented in Oregon can raise AD completion rates as well as hospice enrolments. As location of death shifts from hospital to community, unmet patient and family needs require new clinical skills and health care policies.
Exploration of challenges and success of planning coalition 'Life Planning 2000' in Wisconsin found that the following themes were crucial: commitment, leadership and funding, cohesiveness, working toward a common goal, and educational tool development.	C-	Need for evaluation process. Resources must be commensurate with goals. Strong leadership, paid staff, adequate funding, and the collaboration of diverse groups working towards a common goal are essential.



Key Implications For Practice	Evidence	Issues Of Clinical Significance
Key Ingredients of the La Cross RC experience are: value discussions, key opinion makers, process focus, training of staff, management of program, sustainability, quality improvement, community involvement and institutional support.	D	Gives a possible collection of variables that produces a successful system-wide approach. However, research needs to establish which of these variables are salient for the success of such interventions. Most intractable obstacles are the lack of dedicated resources and lack of commitment of changing health care routines.
In the Oregon experience, action strategies have required data gathering and reporting, and coalition building with a focus on system change. Public education through the news media has proved to be a vital component of Oregon's process of change.	D	Importance of coalition building, evaluation, and public education. Need to focus on minority groups not reached by the current program.
<b>13. System Wide Approach – Communication &amp; Decision Making</b>		
Validation of Patient Centred ACP (PC-ACP) communication approach to patients with chronic illness and their surrogates records higher patient-surrogate congruence, greater satisfaction with decision-making process, and less decisional conflict.	A+	PC-ACP can be an effective approach to ACP. It hinges on its specificity and relevance to patients' medical condition.
Confirms the effectiveness of facilitated discussions about EOL care between patients and their health professionals in terms of defining and documenting patients' wishes for both patients and surrogates.	B	Facilitated discussions about EOL care between patients and health professionals help to define and document patient wishes.
Streamlining of 10 question interview tool – the Living Well Interview. Result indicates two-tailed response defaulting in either generativity or essence.	C	Living Well interview is an effective ACP communication tool
Description and validation of rationale for using an in-depth interview to build and strengthen relationships and to discuss ACP issues.	C	In depth interview is a valuable tool for ACP. Importance of experienced facilitators able to broach a broad range of topics ranging from illness trajectories and treatment options to breaking bad news.

Key Implications For Practice	Evidence	Issues Of Clinical Significance
Quality improvement based on repeated Plan, Do, Study, Act (PSDA) cycle generate deep understanding of complex systems and generates sustainable improvements rapidly.	D	Need to implement a quality improvement system based on measured outcomes.
<b>14. System Wide Approach – Decision Making Tools</b>		
Decisional Conflict Scales (DCS) are a viable research instrument for measuring quality of EOL decision making. However, uncertainty subscale showed a weak discriminating ability and lack of association with the other two subscales, the modifiable factors contributing to uncertainty and the effectiveness of decision making.	B	The DCS may be used to measure quality of EOL decision making.
Within a nursing home context, establishing pathways of care and prioritising pre-defined goals of care may assist clinicians to narrow the range of suitable options when faced with an acute medical problem.	C-	'Pathways of care' in conjunction with pre-defined goals of care may reduce the ethical complexity of medical decision making.
<b>15. System Wide Approach – Administrative Processes &amp; Clinical Routines</b>		
Within a nursing home context, the POST is widely used and effectively limits use of some life-sustaining interventions and potentially improves EOL care.	A	POLST may effectively limit unwanted life-sustaining treatment and improve EOL care.

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