

APPENDIX A.

METHODS

The purpose of this task order is to produce a draft of the Secretary's Report to Congress (RTC) on Advance Directives mandated in Public Law 109-149 (P.L. 109-149). This report reflects three major activities undertaken as part of the task order:

1. development of a focused literature review, including identification and review of existing advance directive and advance care planning efforts;
2. overseeing the selection of commissioned paper writers and managing the development of commission topic-specific papers, and
3. conduct of an expert discussion meeting.

In the sections that follow, the contractor describe the methods used to complete each of the activities under the task order.

Focused Literature Review

In preparation for a National Institutes of Health (NIH) State of the Science Conference on "Improving End of Life Care" in December 2004, RAND conducted a systematic review of the evidence published between 1990 and 2004 regarding the effectiveness of interventions, including advance directives and advance care planning, for improving end-of-life outcomes. The 2004 review was conducted for the National Institute for Nursing Research (NINR) and the Agency for Health care Research and Quality (AHRQ). In this review, the contractor updated the systematic review to include the period 2004-2007 and incorporated new topic areas for the period 2000-2007 not included in the original review.

The contractor addressed the following questions:

- What does the literature say about the utility, feasibility, ethical issues, and success of implementation of advance directives and advance care planning for a diverse array of patient populations and across health care settings?
- What are the salient considerations necessary to more widely apply advance directives in vulnerable populations, such as the cognitively or physically disabled, and in determining what will be a wise course for policy development?
- What are the salient legal considerations regarding the wider promotion of advance directives/advance care planning?
- What are the potential methods that can be used to promote and document advance directives more widely (including the role of health information technology (HIT) and social marketing)?

RAND searched the traditional health literature databases (e.g., MEDLINE, LOCATORplus, Lexus Nexus, CINAHL, EconLit, PsychInfo, and Wilson Select Plus) for relevant publications. These articles involved human subjects, but did not include

individual case reports. To update the original systematic review, we conducted a literature search of articles published in peer-reviewed journals in the United States between 2004 and 2007. We used the literature, search criteria, search terms, protocols, evaluation methods, and materials developed for the original NINR/AHRQ review.

The contractor conducted a separate search of the literature from 2000 to 2007 to identify systematic reviews, randomized or clinical controlled trials, epidemiologic studies, and qualitative studies related to additional topics not addressed in the original review, including legal/policy issues in advance directives/advance care planning; HIT and advance directives/advance care planning; intellectual/physical disabilities and advance directives/advance care planning; and social marketing/public engagement and advance directives/advance care planning.

Our main search strategy, described in detail at the end of the Literature Review on Advance Directives (Appendix B), included a list of terms intended to identify all research publications, within the time period specified, associated with advance directives/advance care planning and with the following topics:

- palliative or end-of-life care;
- global and specific satisfaction with advance directives/advance care planning;
- measures and measurement;
- patient, family/caregiver, and health system factors;
- state legislation, policy, or regulations;
- legal considerations; and
- health information technology.

Additional resources included the Database of Reviews of Effects (DARE), the National Consensus Project for Palliative Care, and where specifically relevant, Health Canada. Each systematic review or intervention/observation study was reviewed by at least one project member for relevance and if relevant was summarized and included in this report.

Topic-Specific Commissioned Papers

The second major deliverable of this task order was the development of topic-specific commissioned papers. As an initial step in this task, RAND worked with the Task Order Monitor (TOM) to determine the specific topics to be covered in these papers. At the project's kick-off meeting, the following topics were selected for the commissioned papers: (1) Public engagement and social marketing efforts around advance directives and advance care planning; (2) Legal and ethical issues around advance directives and advance care planning; and (3) Issues in advance directives and advance care planning for persons with physical, developmental, and cognitive disabilities. RAND also worked with the TOM to identify potential "thought leaders" in

the field to author the commissioned papers. Based on their previous work in these areas, we identified four leaders in the field to write the papers:

1. Myra Christopher and John Carney (Public Engagement/Social Marketing) from the Center for Practical Bioethics, Kansas City, MO. [Appendix E or at <http://aspe.hhs.gov/daltcp/reports/2007/acppe.htm>]
2. Charles Sabatino (Legal/Ethical Issues) from the American Bar Association Commission on Law and Aging, Washington, DC. [Appendix C or at <http://aspe.hhs.gov/daltcp/reports/2007/adacplpi.htm>]
3. Gary Stein (Disability Issues) from the Wurzweiler School of Social Work, Yeshiva University, New York, NY. [Appendix D or at <http://aspe.hhs.gov/daltcp/reports/2007/adacp.htm>]

RAND oversaw the development of the papers with each coauthor. Each contributor developed a draft outline of their respective papers. The outline was revised following comments from RAND and the TOM. Drafts of each paper were written and went through a similar review process and each paper went through two rounds of revision. The final version of each paper was distributed as part of a package of materials sent to Roundtable participants (further described below) and can be found in their entirety in other Appendices.

Roundtable on Advance Directives and Advance Care Planning

The third major deliverable of this task order was to convene Roundtable meetings centering on each of the three commissioned papers (described above). The purpose of the Roundtable meetings was to provide in-depth review and comment on the issues raised in the Literature Review and commissioned papers to help inform the Congressional Report. RAND convened a meeting spanning two days (October 22-23, 2007) at the RAND offices in Arlington, Virginia.

An initial task in this effort was to develop a list of potential Roundtable participants. RAND developed a list of experts in the field. Experts were those persons knowledgeable in the various aspects of advance care planning, including palliative care, bioethics, and current laws and regulations. Potential Roundtable participants were identified through a review of the literature, identifying leaders of national organizations, recommendations from the commissioned paper authors, and suggestions from the TOM. In late July 2007, letters were sent to a preliminary list of experts inviting them to participate in the Roundtable. If an expert was unable to participate in the meeting, we replaced that candidate Roundtable participant with another recommended by the Roundtable candidate, by the commissioned paper authors or the TOM. We aimed to identify ten participants for each of the three Roundtable topic meetings. Approximately three weeks before the Roundtable meetings, each participant received a packet of materials that included the RAND

literature review, the three commissioned papers, an agenda for the meeting, and a list of participants (each of these documents can be found in subsequent Appendices).

Each topic area (public engagement, disability, legal/ethical issues) was the focus of a half-day Roundtable meeting. The meeting was structured in a “modified fishbowl” format, such that the experts participating in one of the half-day Roundtable meetings were actively engaged in a moderator-lead discussion while the members of the other Roundtable meetings and invited guests observed. Each meeting followed a similar format: after a brief introduction to the format of the meeting, the author(s) of the commissioned paper associated with that meeting made a brief (10-15 minute) presentation summarizing the major points of their paper, which was followed by an opportunity for members of the Roundtable to raise and discuss related issues. Observers and members of other Roundtable meetings were allowed to provide written comments, which were provided to the moderator. These prompted additional discussion among the experts around the table. One additional feature was added to the disability Roundtable meeting: Dr. Adrienne Asch and Stephen Drake, both members of the disability Roundtable, were invited to provide brief comments at the outset of the discussion to address “How end of life and ACP would be different if persons with disability were engaged from the start.” Dr. Asch’s comments were transcribed from the meeting and can be found in Appendix G.

In the afternoon of the second day of the meeting, all Roundtable participants were invited to participate in a wrap-up meeting to discuss the underlying assumptions and ideas for improvement of advance directives and advance care planning that had emanated from the three Roundtable topic discussions. These conclusions inform this report. A summary of the meeting can be found in Appendix H.

ADVANCE DIRECTIVES AND ADVANCE CARE PLANNING: REPORT TO CONGRESS

Files Available for This Report

Main Report

HTML: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt.htm>

PDF: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt.pdf>

APPENDIX A. Methods

HTML: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt.htm#appendA>

PDF: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt-A.pdf>

APPENDIX B. Literature Review on Advance Directives

HTML: <http://aspe.hhs.gov/daltcp/reports/2007/advdirlr.htm>

PDF: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt-B.pdf>

APPENDIX C. Advance Directives and Advance Care Planning: Legal and Policy Issues

HTML: <http://aspe.hhs.gov/daltcp/reports/2007/adacplpi.htm>

PDF: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt-C.pdf>

APPENDIX D. Advance Directives and Advance Care Planning for People with Intellectual and Physical Disabilities

HTML: <http://aspe.hhs.gov/daltcp/reports/2007/adacp.htm>

PDF: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt-D.pdf>

APPENDIX E. Commissioned Report: Advance Care Planning and Public Engagement

HTML: <http://aspe.hhs.gov/daltcp/reports/2007/acppe.htm>

PDF: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt-E.pdf>

APPENDIX F. Roundtable Materials

HTML: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt.htm#appendF>

PDF: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt-F.pdf>

APPENDIX G. Adrienne Asch's Comments at the October 2007 ASPE Roundtable

HTML: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt.htm#appendG>

PDF: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt-G.pdf>

APPENDIX H. Summary of the Roundtable Discussions on Advance Directives and Advance Care Planning

HTML: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt.htm#appendH>

PDF: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt-H.pdf>