

Advance Care Planning: Goals of Care - Calgary Zone

LOOKING BACK AND MOVING FORWARD

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LOOKING BACK

- OVERVIEW AND HISTORY OF THE ACP/GCD PROGRAM IN THE CALGARY ZONE
- KEY LEARNINGS RE: POLICY IMPLEMENTATION

MOVING FORWARD

- *ACP/GCD RESOURCES*
- *GOALS OF THE CURRENT TEAM*
- *PROVINCIAL PLANNING*
- CURRENT RESEARCH FINDINGS
- CHART AUDIT DATA
- ACCEPT STUDY

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The “Advance Care Planning: Goals of Care Designation (Adult)” (ACP: GCD) policy was launched across all sectors of the former Calgary Health Region on November 25, 2008. The Pediatric Policy was implemented in 2009.

The implementation of these policies were groundbreaking in Alberta and across the country and continues to guide national standards and practice.

The development and implementation of these policies was a collaborative effort by many clinicians, program leaders and champions, and was led by the Care at the End of Life Initiative.

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The support of ongoing dedicated resources for the integration of this policy has provided the ability to evaluate the progress of implementation and identify outcomes and strategic opportunities for continued growth and improvement

The ACP/GCD policy exemplifies the key AHS strategic directions of quality, access and sustainability.

The policy implementation activities integrate a *quality* improvement approach, resulting in ongoing learning to inform related clinical practices.

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- Access is improved for our patients when there is consensus regarding goals of care. It supports the right care in the right place by being respectful of the patient and family wishes for end of life.
- The policy supports *sustainability* as it assists with the elimination of treatments and interventions considered medically inappropriate or those that do not align with an individual's goals for their care.

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Pre Change

The rationale behind this change:

- Levels of Care are defined differently within the various adult resuscitation policies in the Region.
- There was no established process or framework to support individuals in decision-making about health care goals.
- Documentation of decisions regarding health care was inconsistent.
- Access to documentation of decisions made in other sectors was unpredictable.

The Change

Provides one policy and framework applicable across the continuum.

- Replace Levels of Care with Goals of Care Designations throughout the Region.
- Supports individuals in expressing their wishes and values for health care within the context of medically appropriate treatments.
- Works to ensure that the outcomes of discussions are documented and available to all health care teams.

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Key Features of the Processes & Policy

- Focus is on the Goals of care
- A Patient Centric Approach that integrates patient's values, wishes and goals in the context of medically appropriate treatment
- Ensures infrastructure and processes to support Advance Care Planning.
- Decisions are honored system wide with a process of documentation and communication to ensure this.
- Congruent with the Personal Directives Legislation
- Provides the framework and tools for clinicians to be able to meet the criteria of the policy
- Provides resources for individuals and families to engage in advance care planning
- The Goals of care are based on ACP conversations
- Goals of Care and wishes change over time
- Provides direction regarding interventions, and location of care.

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Adult vs Pediatric Policy

- Applies only when clinically relevant
- Respects child/family dynamic
- Location of care options unique to pediatrics
- Provision for Mature Minor

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Process of arriving at a Goals of Care Order



- R** Medical Care and Interventions including Resuscitation followed by ICU
- M** Medical Care and Interventions, excluding Resuscitation
- C** Medical Care and Interventions, focused on Comfort

- Diagnosis
- Prognosis
- Anticipated Outcomes
- Wishes and Values
- Life Support / Life Sustaining Benefits
- Comfort Measures
- Resources

- Cure or control of condition with option for resuscitation
- Cure or control, no resuscitation
- Alleviate the symptoms

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Goals of Care Designations		Interventions							
		Chest comp.	Intubate	Resuscitation	ICU	Site transfer	Surgery	Life sustaining	Symptom control
R Resuscitative Care	1	✓	✓	✓	✓	✓	✓	✓	✓
	2	✗	✓	✓	✓	✓	✓	✓	✓
	3	✗	✗	✓	✓	✓	✓	✓	✓
M Medical Care	1	✗	✗	✗	✗	✓	✓	✓	✓
	2	✗	✗	✗	✗	Only for symptom control		✓	✓
C Comfort Care	1	✗	✗	✗	✗	Only for symptom control		✓	✓
	2	✗	✗	✗	✗	✗	✗	✗	✓

ACP/GCD Calgary Zone Resources

www.albertahealthservices.ca/advancecareplanning.asp

Adults:

- My Voice Planning Ahead Video
- My Voice Planning Ahead Brochure
- Understanding Goals of Care Designation Brochure
- My Voice Workbook
- Goals of Care Designation Order Form
- ACP Tracking Record
- Quick reference pocket cards and posters

Pediatrics:

- Hear My Voice - an activity for families who are coping with a potential illness to encourage them to talk about their values and goals to guide decision making during the illness experience.
- Hear Our Voice - workbook for parents and guardians to support advance care for children and youth.

ACP/GCD Calgary Zone Resources

www.albertahealthservices.ca/advancecareplanning.asp

- Advance Care Planning and Goals of Care training modules for Adults and Pediatrics
- Adult and Pediatric policies
- Links to relevant resources and sites

Key Learning Regarding GCD/ACP Implementation

Themes:

- Leadership & Accountability
- Education
- Communication and Engagement Strategies
- Resources
- Evaluation and Quality Improvement

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MOVING FORWARD

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- Setting New Vision For the Work
- The Current Team
- Continued Integration of the Policy
- Working with strategies from the chart audit report
- Engagement with clinicians, patients and public
- Establishing educational methodologies
- Reviewing all tools and resources
- In collaboration with provincial work

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Team Roles:

- Bev Berg, Coordinator
- Dr. Jessica Simon, Physician Consultant
- Chandra Vig, Education Consultant
- Tracy Lynn Wityk Martin, Quality Improvement Specialist
- Tannis Dorscht, Administrative Support

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Advance Care Planning is a Process that involves

1. Thinking about values and wishes regarding future health care choices.
2. Learning about medical information that is relevant to their health concerns
3. Choosing an agent and Communicating wishes and values to a designated agent, loved ones and health care providers.
4. Documenting choices, wishes and values.
the designated agent(s), loved ones and health care provider

An Advance Care Plan

- Advance care plans are verbal or written instructions, made while the individual is still capable, describing what kind of care they would want (or not want) if they become incapable of communicating to others.
- These plans are made by the individual. No one can make an advance care plan for another person.
- To be eligible to make an advance care plan in Alberta an individual must be at least 18 years old and be capable of understanding the nature of consequences of their health care choices.
- Advance care plans communicate when the individual is not able to. The plan, whether verbal or written, becomes their “voice”.
- As long as a person is able to understand their health care providers, and can communicate for themselves, doctors, nurses and other health care providers will talk to them about their preferences for health care.

A **Personal Directive** is a written document that enables individuals to give direction and clarification to health professionals and other service providers in accordance with the Personal Directives Act (Alberta). A Personal Directive is effective legally only when the maker of the Personal Directive lacks capacity. While a Personal Directive from another Province or Country may not be valid in Alberta, the document may serve as a guide to help decision-making.

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This work continues to be relevant for a number of critical reasons:

According to Statistics Canada:

- **248,000** Canadians die each year
- In 2020 this number will have increased to **330,000**

According to the 2009 CHPCA roundtable on Advance Care Planning:

- Up to 50% of persons cannot make their own decisions at the end of life (CHPCA)
- Health professionals typically treat when uncertain of treatment wishes
- Hospitals remain the major provider of EOL care as 70% of Canadians die in a hospital with one in five of these hospitalized deaths occurring in an ICU
- Loved ones have a significant chance of not knowing a person's view without discussion

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Current Research demonstrates:

- The absence of Advance Care planning is associated with worse patient and family ratings of quality of life in the terminal phase of illness
- Those who have end of life conversations with loved ones and health care professionals:
 - Require fewer aggressive medical interventions at the end of life
 - Are more likely to take advantage of relevant resources at end of life
 - Surviving family feel less of a burden with decision making and have reduced suffering/distress in times of bereavement.

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Advance Care Planning is a personal issue for everyone. None of us know when we might be involved in an accident or have a physical event that makes it impossible for us to communicate our preferences for medical care.

We can all become seriously ill, incapacitated, or be diagnosed with a medical condition that may slowly take away our ability to communicate. Planning ahead helps those we are close to, and health care agents, know and understand our wishes to guide health care decision making.

What we ask of others we should consider for ourselves.

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Karen Ann Quinlan 1975 age 21

Nancy Cruzan 1983 age 25

Terri Schaivo 1990 age 26

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Engage With Grace - The One Slide Project

<http://www.engagewithgrace.org/>

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- The relevance of ACP/GCD varies according to health conditions and needs.
- Many chronic conditions have an illness trajectory that can be predicted. Advance care planning enables individuals to investigate treatments as their condition progresses, including the option to trial specific interventions. Calgary Zone story.
- Seniors live with an awareness that they are nearing the end of their lives and often worry about being a burden to their families. They have experienced the death of friends which may encourage them to plan for their own end of life.
- ACP research is more prevalent in the last ten years and often focuses on these populations.

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Common Barriers and Facilitators for engaging in ACP are:

Patient Barriers

- Perceiving ACP as irrelevant
- Relationship concerns – worried about discussing this with loved ones
- Need for more information
- Time constraints in medical encounters
- The Fear of having discussions regarding end of life care

Patient Facilitators

- More willingness to engage in ACP with individuals who have experienced or witnessed end of life care in loved ones
- Not wanting to be a burden on loved ones
- Understanding of life support/ sustaining interventions and the benefits of treatment
- Compassionate conversations about end of life care

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HCP Barriers:

Lack of confidence and skills in engaging in the conversation

Time constraints

The nature of the dialogue

Fear of taking away hope

HCP Facilitators

Skills and confidence in engaging in conversations

Patient experiences

Personal Experiences

Current Research

- In a study conducted by Detering et al,(2010) in Australia 309 medical inpatients aged 80+ were followed for six months or until death.
- Randomized to two groups – usual care and usual care with advance care planning
- Of the group randomized to ACP 84% expressed wishes or appointed a surrogate, or both
- Of the 56 patients, of the total study, who died by six months end of life wishes were more likely to be known and followed in the intervention group than the control group, family members had significantly less stress, anxiety and depression and patient and family satisfaction was higher.
- These authors identify that without the documentation of patient wishes patients may be cared for in a way they would not have chosen at the end of their life. “The process of advance care planning informs and empowers patients to have a say about their current and future treatment”. P,1.

Current Research

- Silveira et al (2010) reported the results of an observational, longitudinal study of 3756 elderly Americans and found that the majority need decision-making at the end of life at a time when they lacked the capacity to make decisions
- Patients who had prepared advance directives received care that was strongly associated with their preferences and the majority preferred limited care or comfort care (only 1.9% wanted all care possible).

Current Research

- In another observational study of terminal cancer patients conducted by Wright et al., 2008, the absence of ACP in any of its forms was associated with worse patient ratings of quality of life in the terminal phase of the illness, worse ratings of satisfaction by the family during the terminal illness, and increased family ratings of anxiety and depression.
- In contrast, when physicians and patients/families engage in ACP, there is less ‘intensification of care’ (use of intensive care units, life-sustaining technologies, or feeding tube insertions) and more usage of hospice services.
- Surviving caregivers experienced less regret and showed overall improvements in quality of life during the bereavement period.

Current Research

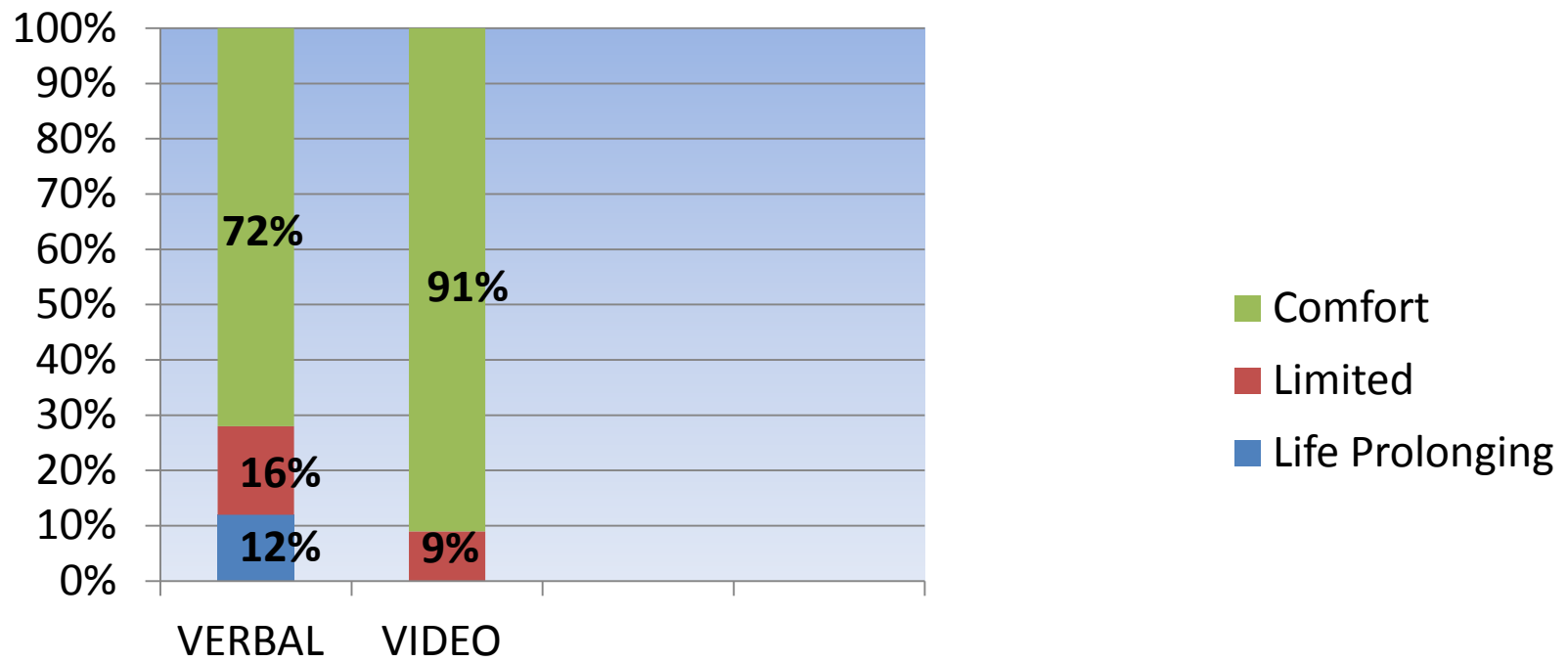
Patient Education Videos

<http://www.acpdecisions.org/home.html>

ACP Patient Education Videos have been developed by the Nous Foundation in the USA to help patients make informed decisions. It is a patient-centered supplemental tool to reinforce information introduced by the clinician that empowers patients and their families to make informed decisions consistent with their values. The use and development of video aids is capturing great attention regarding a more informed method of ACP and determining goals of care.

Volandes et al., 2011)

Conducted a randomized controlled trial of a video decision aid of the goals of care in advanced-dementia among a diverse group of elderly patients in a rural community.



Current Research

El-jawalri, et al. (2010) conducted a study to determine if a a goals of care video to supplement a verbal description improved end of life decision making for patients with cancer.

Participants who viewed the video were more likely to prefer comfort care and void CPR.

In both studies the majority of patients:

Felt comfortable watching the video

Would recommend it for other patients to view

Felt that it improved their understanding of levels of care and interventions

<http://www.cbsnews.com/stories/2011/06/01/eveningnews/main20068123.shtml>

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- Three chart audits have been conducted to measure the success and guide the continued integration of the policy across all adult health care sectors in the Calgary Zone.
- These audits occurred at baseline (before implementation), and at 6 months and 18 months post implementation.

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A total of 947 charts were reviewed in Summer/Fall 2010 across all sectors:

- Acute Care (3 urban sites (9 units), 2 rural sites)
- Home Care (Palliative and Seniors Teams)
- Designated Assisted Living (2 DAL sites)
- Long Term Care (LTC; 4 urban, 1 rural)
- Hospices (3 sites)

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- Charts were randomly selected from those that focused on patients that would be most likely to require a Goals of Care Designation (GCD) and to benefit from Advance Care Planning (ACP) (including 50 years of age and older and targeted units/teams).
- The results may not be generalizable to the overall patient/client population served in these sectors.
- All charts reviewed in this third phase of the chart audit were of current patients.

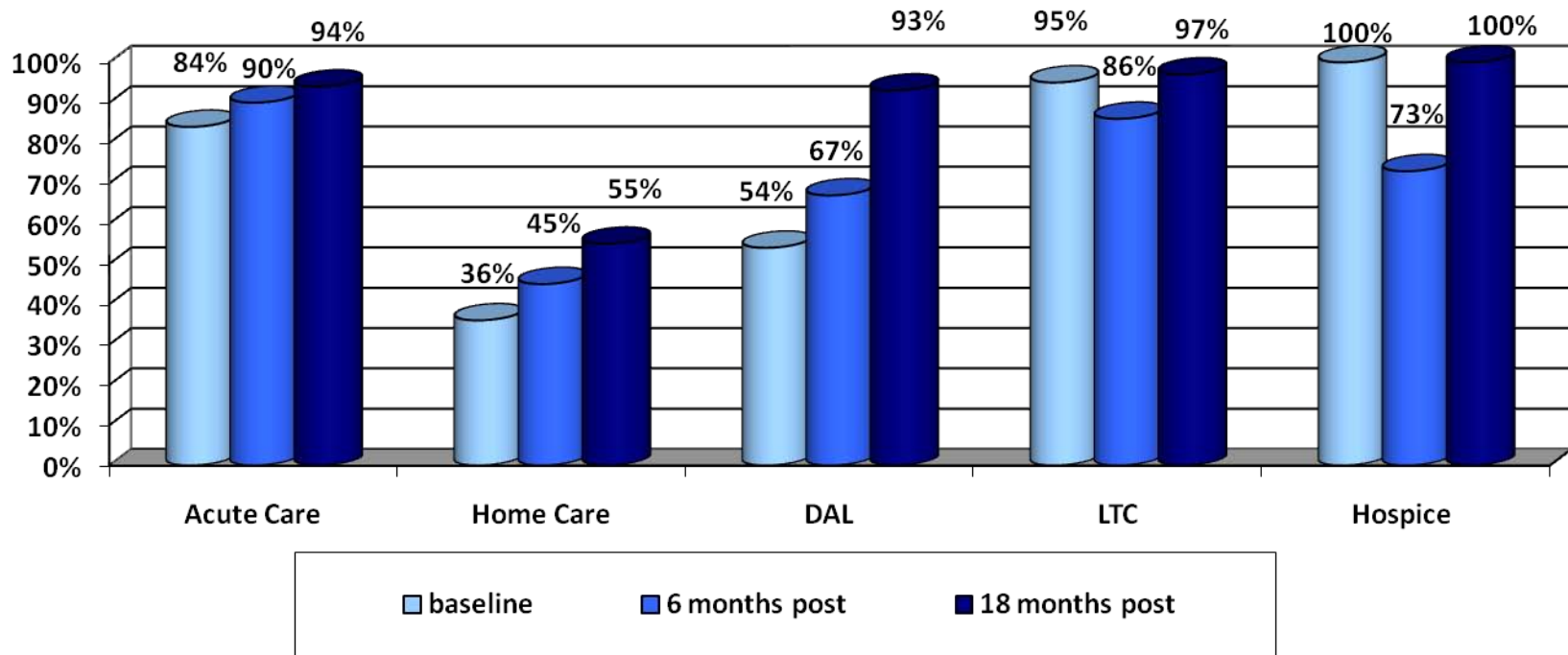
Outcomes

Outcome 1: “Advance Care Planning: Goals of Care Designation (Adult)” policy has been successfully implemented across AHS, Calgary Zone - **Achieved**

Outcome 2: Information related to future health care decisions transferred across the service streams - **Achieved**

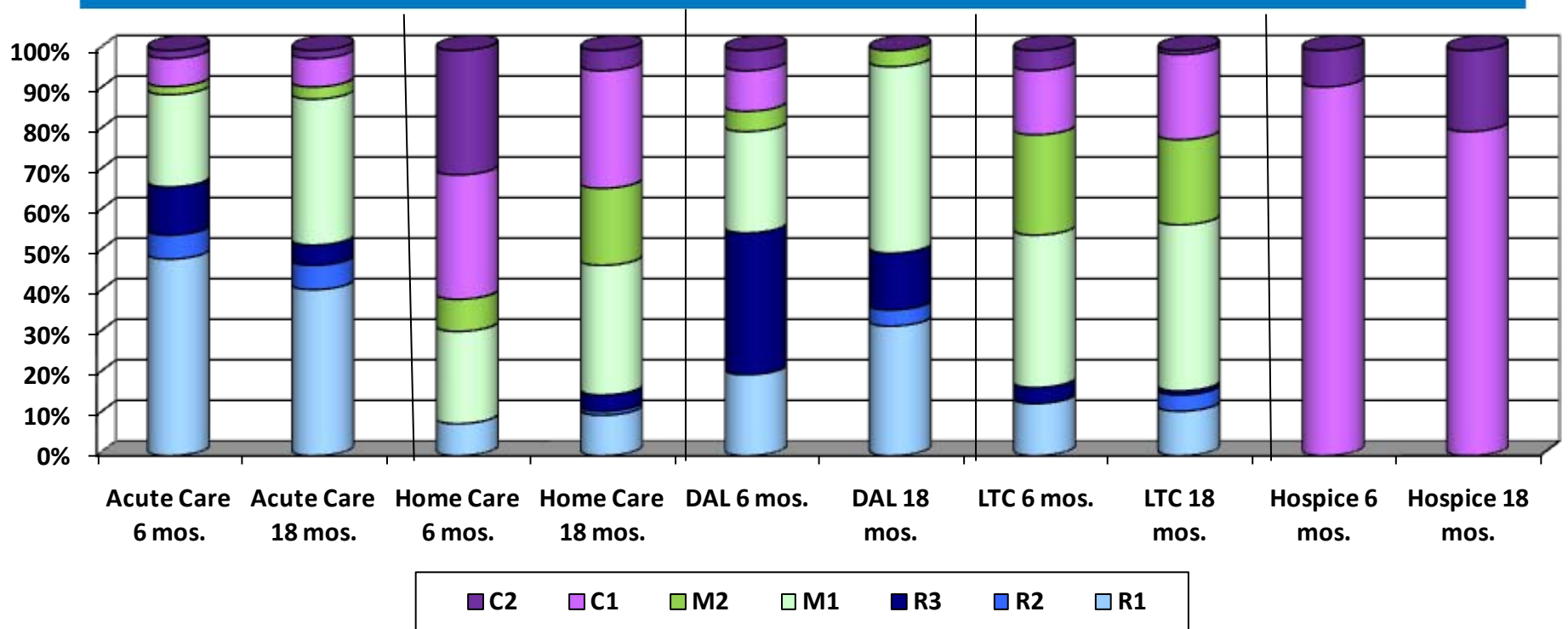
Outcome 3: Patients' preferences as identified in their medical charts and/or advance directives are followed as they receive medically appropriate end of life care - **Achieved**

Presence of Goals of Care Designation (GCD) Order



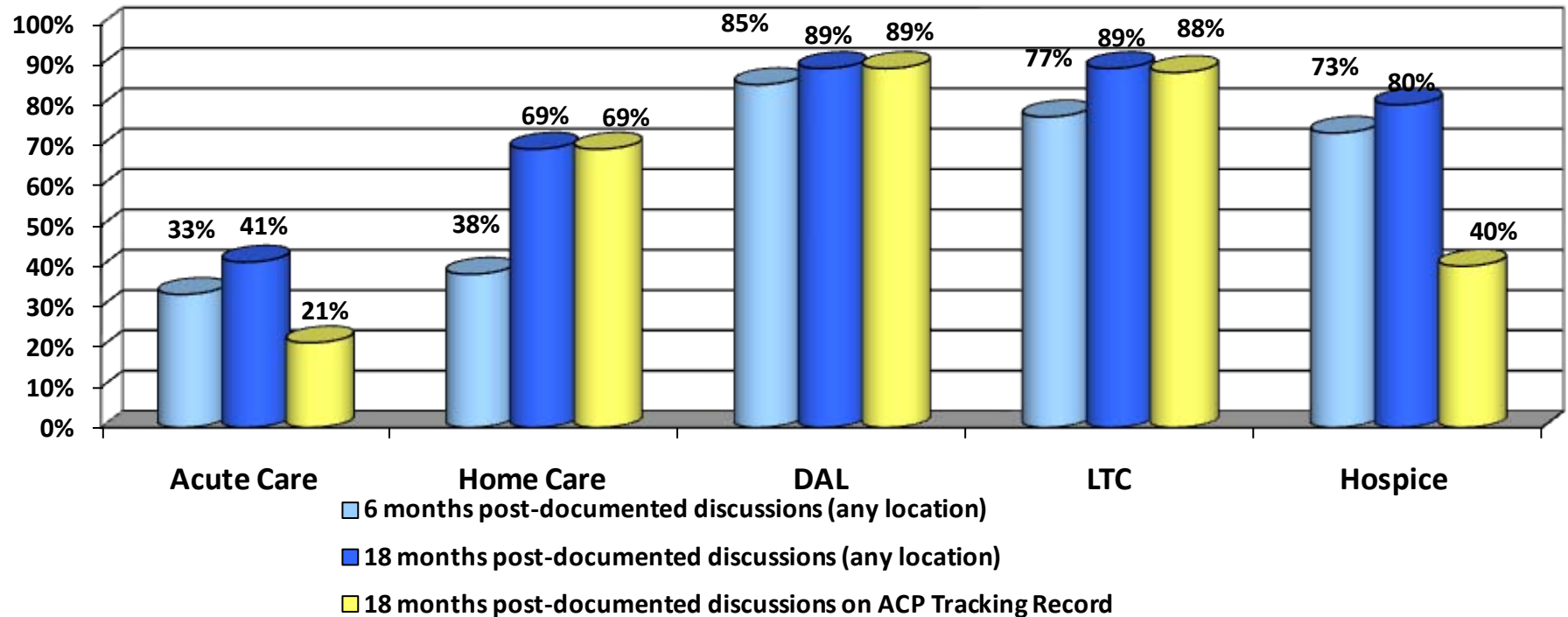
The Practice of issuing Designation Orders, reflecting Goals of Care continued to improve across all sectors

Distribution of GCDs



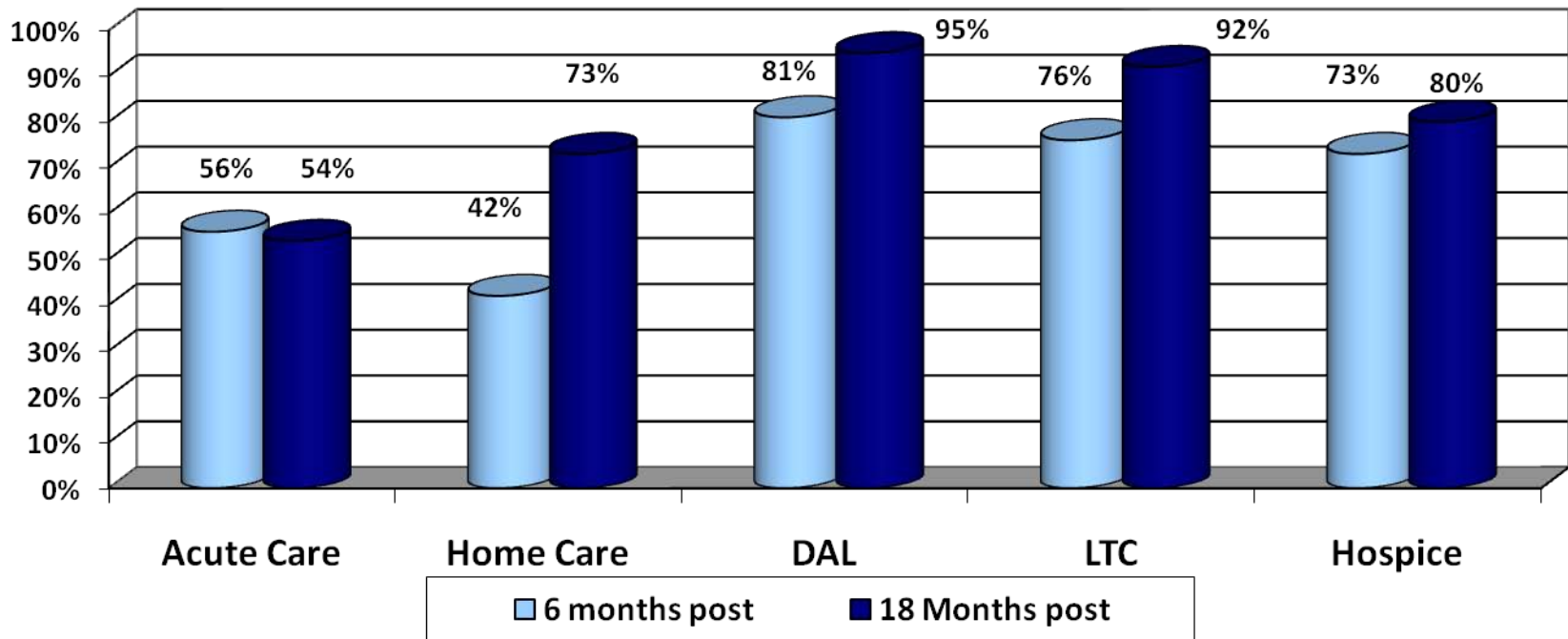
Distributions of GCDs varied by sector and appeared to reflect the general acuity and goals of care for the various populations served.

Documentation of ACP Discussion (patients with a GCD)



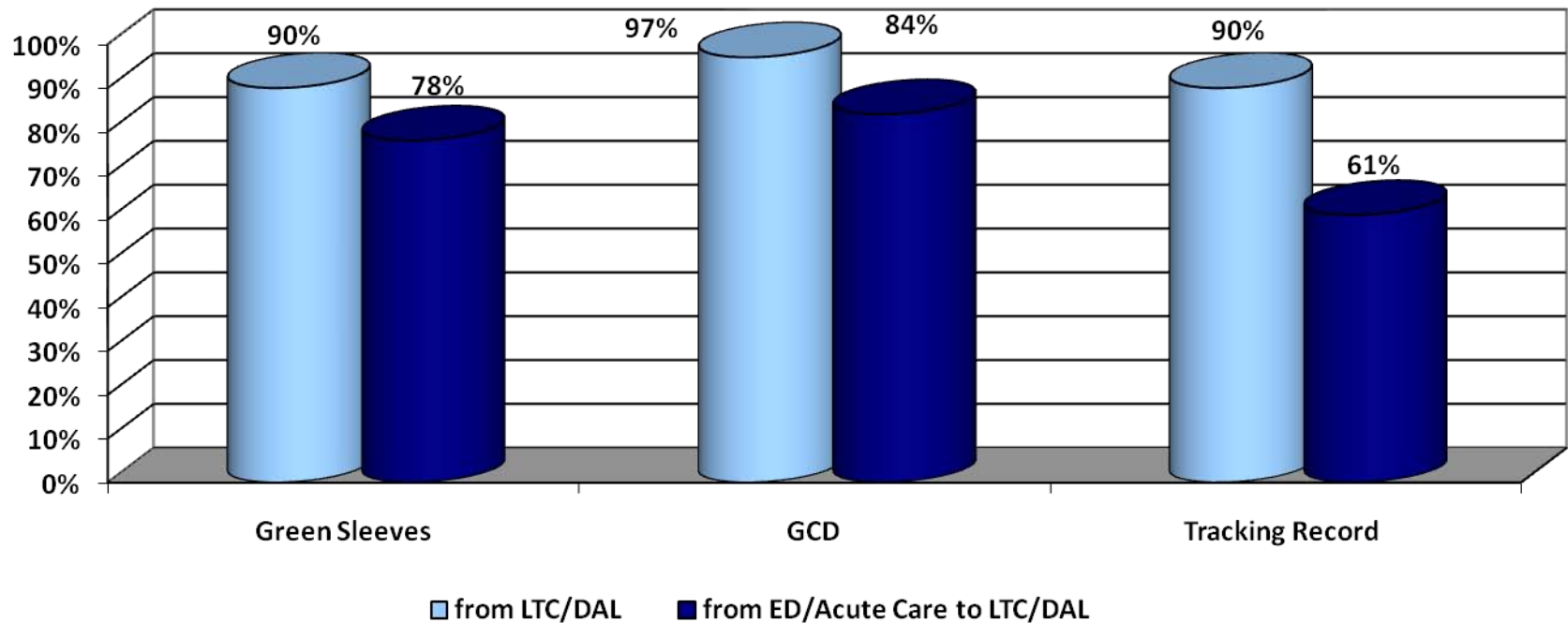
Every sector increased the percentage of charts that had any Documentation of Advance Care Planning/Goals of Care discussions from baseline to 6 months to 18 months post policy implementation (except for DAL, which maintained its 6 month post policy rate).

Documentation of Goals of Care Discussions : Patients with nonR1 GCDs



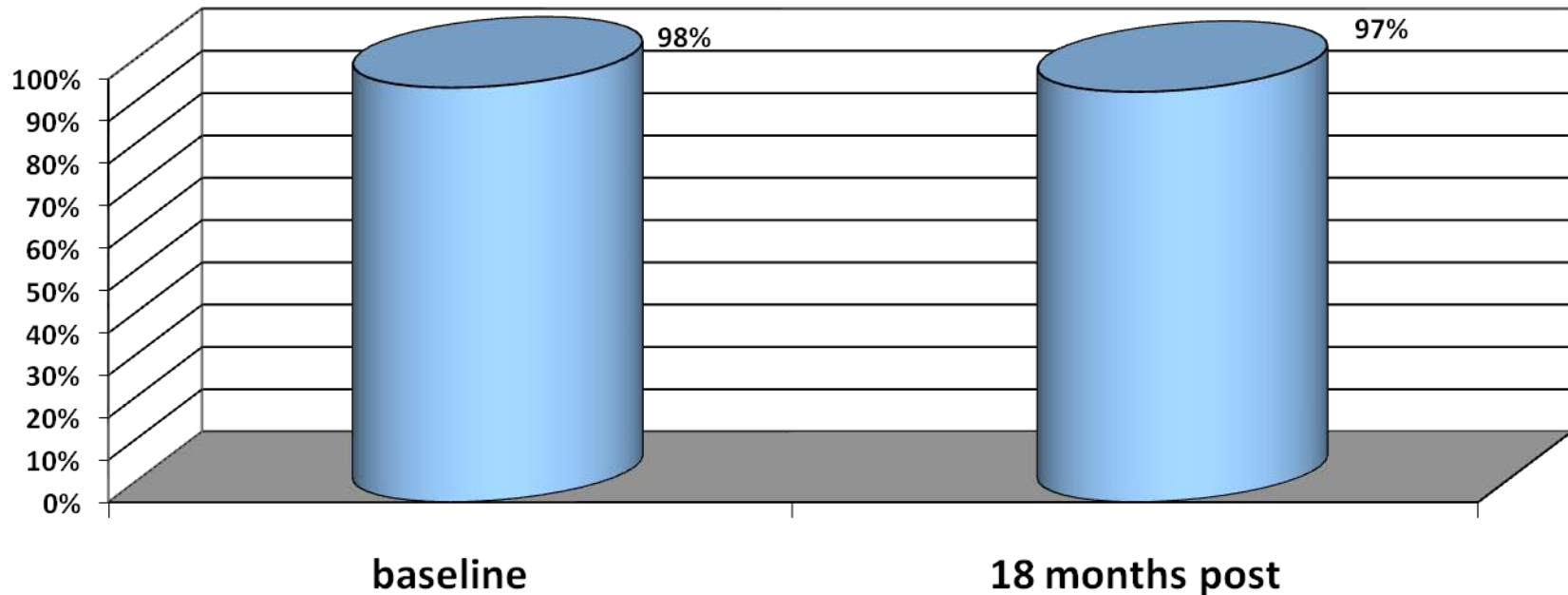
The percentage of charts with documentation of Goals of Care discussions (anywhere on the chart) for patients with non R1 GCD's increased from 6 months to 18 months post policy implementation (except for Acute Care, which remained similar).

Transfer of Information between LTC/DAL and ED/Acute Care



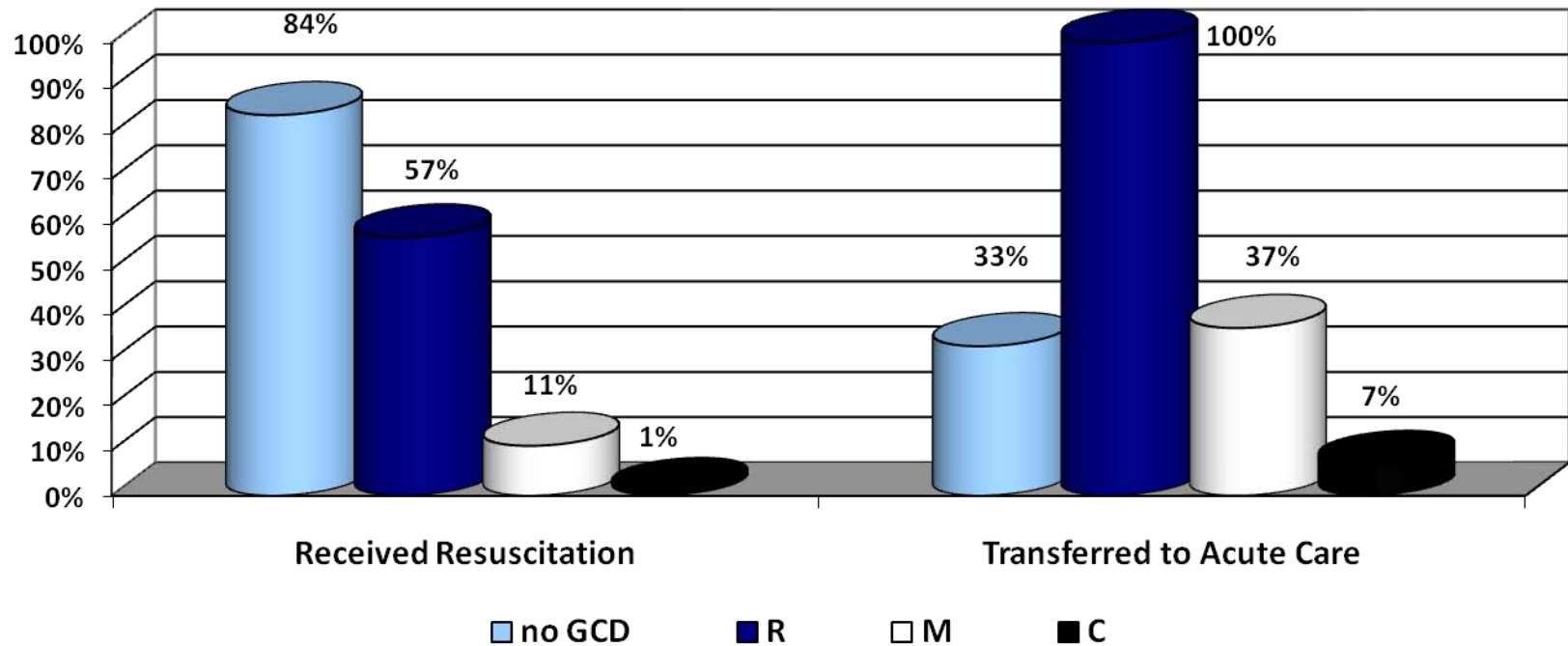
Eighteen month's post policy 'go live', policy related tools and documents transferred with patients between Acute Care/ED and LTC/DAL

Preferences Followed at End of Life



Across all sectors, patient preferences for future health care decisions as documented in their medical charts were followed almost 100% of the time.

Resource utilization of Deceased Patients by GCD



Resource utilization differed for those who died with a GCD order versus those that died without a documented GCD order.

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Areas for Quality Improvement : Next Steps

1. Enhance the use and transfer of the ACP Tracking Record
2. Education and Quality Improvement activities regarding the transfer of information between service streams
3. Advance Care Planning discussions – enhance clinician comfort, skill, and documentation
4. Engaging physicians in the community regarding completing GCD Orders
5. Additional public education to increase comfort with ACP/GCD discussions and process
6. Conduct research regarding the patient/family's experience and perspective of ACP/GCD - The ACCEPT Study