

# Implementing and assessing the acceptability of a portable, readily accessible, and actionable end of life planning tool for patients with advanced serious illness or frailty in southern New Zealand

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## ABSTRACT

The Clinical Order Articulating Scope of Treatment (COAST) form was designed as a single-page medical order documenting and communicating the resuscitation status and scope of appropriate medical treatment for adult patients believed to be in their final year of life. Prior to introducing COAST, each health provider or agency in the Southland Region of New Zealand had its own forms and processes; the COAST pilot attempted to consolidate and streamline these varied processes into one actionable medical order that is valid throughout the region. This three-phase initiative involved piloting use of the COAST form in Southland between May 2019 and January 2020. Surveys were given to patients at the time of COAST form completion and distributed electronically to health professionals at the end of each phase to assess attitudes towards COAST form use and obtain feedback. The hypothesis was that COAST would be acceptable to patients, families, and health providers. The response rates for patient and health professional COAST experience surveys were low (24% and 27% respectively) but the feedback was positive, with the majority of respondents expressing that the COAST form improved patient care. Implementation of the COAST form has been widely accepted by patients, families, and health professionals alike.

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Advance care planning is an individualised process of discussion and shared decision making for future healthcare.<sup>1</sup> An Australian study from 2010<sup>2</sup> found that elderly hospital inpatients with an advance care plan (ACP) were more likely to have their end of life wishes known by their doctor and had higher levels of patient and family satisfaction than those without an ACP. Potential barriers to ACP completion that were identified included availability of staff, confidence to discuss advance care planning with patients, and ensuring that doctors understood and supported advance care planning. Generating and implementing ACPs with patients and their whānau is a competency of both general practice training and physician specialty training in New Zealand.

Generally accepted best practice is to discuss and document end of life treatment preferences well in advance of the need for treatment, primarily due to concerns that patients may be unable to participate in such planning or communicate their wishes

when the time comes. Toolkits such as the Aotearoa Serious Illness Conversation Guide<sup>3</sup> can be used to guide these discussions. As advance care planning is typically done prior to the diagnosis of a serious, life-limiting illness or significant infirmity, there may be a gap of weeks, months, or years between when an ACP discussion occurs and when the plan is actually implemented. Unfortunately, the scenarios anticipated when an ACP is prepared may look very different from the clinical picture that eventuates. Conversely, waiting too long to engage in advance care planning can result in late hospice referral and unhelpful or unwanted transitions between healthcare settings in the final weeks or months of life. In 2013, Teno and colleagues<sup>4</sup> reported that transitions during the last 90 days of life for patients with cancer, chronic obstructive pulmonary disease, and dementia in the United States increased from an average of 2.1 per decedent in the year 2000, to 3.1 in 2009, despite increased use of hospice support and considerable promotion of advance

care planning. As patients with advanced dementia lack the capacity to complete and sign an ACP document, this vulnerable population is at even greater risk of experiencing unwanted, unhelpful and/or potentially burdensome treatments and transitions at end of life.

In March 2011, the Goals of Care (GOC) clinical framework was introduced at Royal Hobart Hospital in Tasmania as part of a Healthy Dying Initiative. The GOC form stratifies patient care into one of three possible phases: curative/restorative, palliative, or terminal. The GOC plan is formulated with the patient or surrogate decision-maker. The form itself is signed only by the clinician, as the developers intended it to be a clinical directive as a culmination of ongoing medical assessment and communication, rather than a patient directive along the lines of ACP. A retrospective audit of admissions to the hospital's assessment and planning unit found that Not for Resuscitation forms were completed for only 34% of admitted patients in August 2009 (prior to the initiative), whereas GOC forms were completed for 75% of admitted patients in August 2011.<sup>5</sup> The initiative was associated with improved hospital recognition of the dying process and was found to be safe, effective, and widely acceptable, with no associated reportable incidents or complaints.

In New Zealand, there are a variety of ACP documents and forms being used, and there is no consistent, portable document that is recognised and honoured across all care settings. For example, a patient and their general practitioner may complete an ACP and "Do Not Resuscitate" order at an aged residential care facility, but that signed order would not be recognised if the patient is subsequently transferred to an acute care hospital. Each aged residential care facility, hospital, and hospice provider has its own advance care planning and ceiling of treatment order process. Patients/families are often asked to clarify and document treatment preferences with each transition; this has the potential to negatively impact perceptions of healthcare quality and coordination.

In 2018, Nelson Marlborough Health piloted use of a 2-page document titled Options for Treatment and Resuscitation, or OtTER.<sup>6</sup> Use of this tiered resuscitation form resulted in improved documentation and visibility of goals of treatment decisions compared to the existing Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) form. Canterbury District Health Board have also developed a 2-page DNACPR order that

incorporates free-text fields to document any additional diagnostic and treatment preferences, the rationale for the DNACPR decision, and details of the pertinent discussions that have occurred. Both initiatives are used in the acute hospital setting but have not been widely incorporated into the outpatient or aged residential care setting. To our knowledge, no similar initiatives exist in the North Island.

This pilot initiative involved the development and implementation of a one-page medical order used to provide appropriate and goal-directed care for adult Southern District Health Board (SDHB) patients with serious medical illnesses or frailty and an expected prognosis of 1 year or less. The document is titled Huarahi Rangimārie, a Māori term which translates to "peaceful path" and is a Clinical Order Articulating Scope of Treatment (which became known as a "COAST form"). The intervention was not designed to influence discussions around ACP, but rather to consolidate multiple forms and processes into a one-page universally accepted medical order.

The aim of the study was to assess the acceptability of the document to healthcare professionals involved in its use, as well as patients and/or proxy decision makers. Ethical approval for this project was obtained from the New Zealand Health and Disability Ethics Committee (Reference 19/STH/44).

## Methodology

### COAST form development

The pilot COAST form (Appendix 1) was developed over a 4-month period by the investigators, and the layout was revised following an initial stakeholder's meeting at Hospice Southland, which introduced the proposed COAST form and process to local health providers and solicited feedback. A logo was then created and added to the form alongside the Southern DHB and Hospice Southland logos. Pre-COAST data questionnaires were distributed to gauge the current practice around ACP (Appendix 2).

### Education

Education regarding the rationale for the study and the introduction of the COAST form was then delivered to local healthcare providers by presenting at Hospital Grand Rounds, holding evening education sessions at Hospice Southland, conducting on-site health provider education sessions, delivering written information, and also producing an educational video which was

available on the COAST website ([www.COAST-form.net](http://www.COAST-form.net)).

### Eligibility

All adults >18 years were eligible to be included if they were deemed to be in the final year of life due to advanced, progressive illness and/or frailty as identified by a doctor or nurse practitioner for whom the clinician answers “no” to the surprise question: “*would you be surprised if this patient died in the next 12 months?*” Patients were excluded if they were under the age of 18 years, or they did not consent to involvement in the study.

Health professionals who completed at least one COAST form were invited to complete an online survey at the end of each phase.

### Recruitment

Patients were recruited in three phases, each lasting three months, to allow staggered education sessions for health professionals in each area, and to allow the study coordinator to manage the data in a timely manner. Figure 1 demonstrates the geographical roll out of the pilot project.

Written information regarding the COAST form and process was provided to patients identified as eligible to participate, and written consent was obtained from patients who agreed to participate. Patients who were unable to provide written consent were included if it was deemed by their health provider to be in their best interest, and with permission from the proxy decision maker.

### Implementation

Phase one invited all eligible Southland Hospital inpatients, patients referred to the Southland Hospital Palliative Care Advisory Service, and patients admitted to the Hospice Southland programme to engage in the COAST process. Forms were completed by both hospice and hospital medical staff.

Phase two invited all eligible residents in aged residential care in the Invercargill area to participate, with general practitioners being invited to complete forms, and phase three incorporated all eligible residents within the Southland Region in hospice, hospital, general practice, and community settings.

The project was overseen by a volunteer COAST Steering Committee consisting of a nurse practitioner working in aged residential care, a rest home clinical manager, two local GPs, the Māori

chaplain working at Southland Hospital, and two hospice patients. This steering group was formed to guide COAST study implementation, provide stakeholder perspectives, and champion the project. Members were active in troubleshooting and offering suggestions throughout the study period. Meetings were convened by the study investigators and nurse study coordinator, and the committee met on 17 April 2019 (prior to the study commencing) and then at the end of each of the three study phases.

### Data collection

Patients and/or proxies were given a survey to complete following completion of the COAST process (Appendix 3), along with a postage-prepaid return envelope. An electronic survey was distributed at the end of each implementation phase to address the aim of elucidating health provider satisfaction with the COAST form and process, and any enablers or barriers to COAST form completion (Appendix 4). Surveys generated primarily descriptive data.

Completed feedback forms were received by the study coordinator at Hospice Southland; data were uploaded to a spreadsheet and held securely.

### Results

One hundred and eighty-three patients consented to be involved in the study, with 207 COAST forms completed. COAST forms were updated to reflect new treatment goals in 21 patients.

#### Pre-COAST survey

Twenty-two responses were received for the pre-COAST survey, which was distributed after the stakeholders’ meeting. Responses were received from 10 GPs (45%), two other doctors (9%), two nurses (9%), two identified as “other” (9%), and six respondents left this section blank.

Nineteen out of 22 had experience with advance care planning (86%):

*“I attended the 2-day ACP course but have had difficulty implementing.”*

*“Very time consuming, means often not done.”*

Twenty-one out of 22 respondents (95%) viewed a Not for Resuscitation form as being different from an ACP.

All respondents thought the introduction of the COAST form would be beneficial to them:

*“One page form which is easier to use. More effective and clear for planning of care.”*

*“Great, single page, simple.”*

Three respondents suggested incorporating an area for optional patient signature on the COAST form.

The main barriers identified to COAST form implementation were time needed to discuss the options and complete the form, and IT issues such as differing systems between establishments.

### Patient survey

Questionnaires were completed and returned by 37 patients or family members—a response rate of 20%. The majority of respondents were patients (27, 73%), with 27% (6) of surveys completed by the activated Enduring Power of Attorney (EPOA), 8% by a family member, and one did not specify a relationship (3%).

Ninety-two percent were familiar with the idea of Advance Care Planning, and 25 out of 37 respondents had completed an ACP. Thirty-five (95%) respondents had spoken with someone they trust (e.g., friend, family member, EPOA), and 27 (73%) had spoken to their doctor about what treatments they would or wouldn't want if they were seriously ill or dying. Thirty-two (86%) of respondents were familiar with the COAST form.

Figure 1 demonstrates the responses to the free-text comments about the purpose of the COAST form represented as a word cloud.

Seventy percent of respondents (26) had completed a COAST form for themselves and seven (19%) had been involved in COAST completion for someone else. Seventy-eight percent thought the COAST form was explained well. Thirty-five percent of respondents felt having a COAST form had made no difference to their/the person's healthcare, 22% felt it had made the care somewhat better and 27% felt that it made the care a lot better.

Sixteen respondents stated that they had no concerns about the form or process. Free-text comments included:

*“I want everybody to listen to me and know what I want. I'm afraid*

*that some nurses may not follow the COAST form information.”*

*“More people throughout New Zealand need to know about COAST. It should be mandatory for all adults.”*

Seven respondents stated in the free-text comments that they were supportive of the project, with one respondent writing *“I believe it is a valuable document that everyone should have”* and another stating:

*“I'm in agreement with COAST because it is my choice and I want to make my opinion clear. I understand my healthcare will not be compromised. It is a good idea which gives peace of mind to me and those I love.”*

### Practitioner survey

There were 14 survey respondents by the conclusion of the pilot. Fifty-four practitioners completed COAST forms; two of these were study investigators, so were excluded from the survey. The response rate was 27%. The majority of respondents (seven) worked in General Practice; six respondents worked at Southland Hospital and one at Hospice Southland.

The word cloud in Figure 2 depicts what health professionals knew about the COAST form and process.

Fifty percent of respondents had completed between one and three COAST forms, with 21% completing between four and nine forms, and 29% completing more than ten forms. All 14 respondents felt they had adequate education and training about the COAST form and process.

What practitioners thought worked well about the COAST form and process:

*“One form, good summary, easy to use.”*

*“It is a good trigger to have these discussions.”*

*“Concise, clear and easy to access.”*

*“Clear form and shared across GP/Hospital and Hospice.”*

*“It sets clearer expectations when patients arrive to the ED with acute*

*illnesses. It also gives patients/whānau a framework for dealing with end of life discussions and ceilings of care. The patients I've had who have had a COAST completed had an understanding of supportive care, dying with dignity and aggressive medical intervention."*

Thirteen out of 14 respondents either "somewhat agreed" or "completely agreed" that the COAST form improved the care provided to their patients, as shown in Figure 3.

Respondents identified the following barriers to COAST form completion:

*"Taking time to have the conversation."*

*"GP consults too short to do it justice."*

*"Lack of awareness among health professionals and patients."*

*"Uncertainty of patient prognosis."*

All respondents were "somewhat comfortable" or "very comfortable" completing the COAST form. All respondents were "somewhat comfortable" or "very comfortable" following COAST form orders if they did not complete the form themselves.

Feedback on how the COAST form could be improved:

*"Make it online."*

*"Clarity on how it gets disseminated to GP/ambulance/ED/hospital records."*

*"Clarify what selective treatments a person agrees to; clarify if oxygen etc. is part of comfort care."*

Other free-text comments were positive about the introduction of COAST forms:

*"Been very positive experience using COAST forms—generally process is liked by patients and families."*

*"I think it's a great initiative and has certainly benefited the patients I've interacted with."*

*"It is an organised way of having a hard conversation."*

*"I agree with keeping to one page; make it electronic immediately available on HealthOne and accessible to St Johns."*

## Discussion

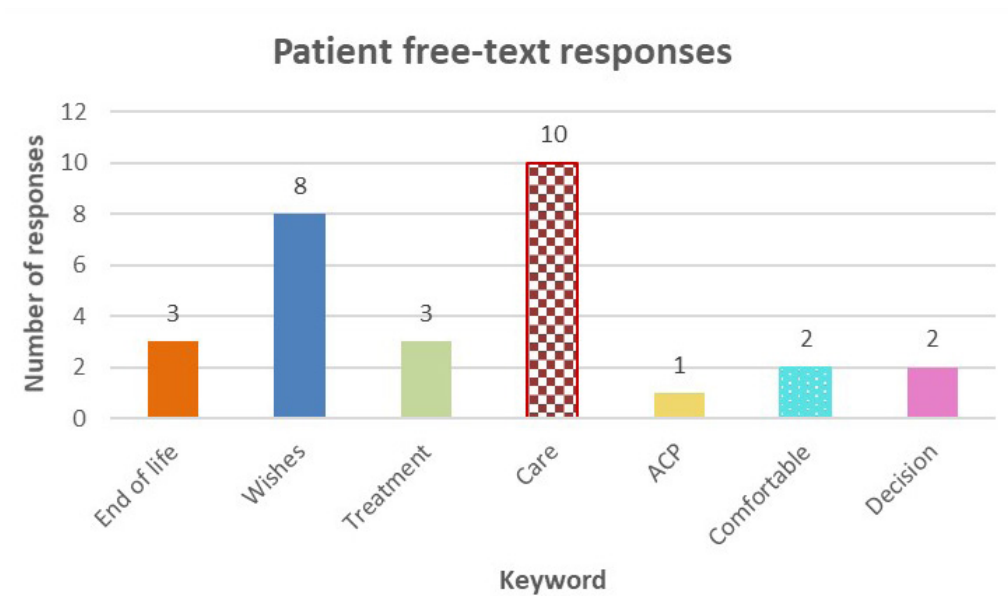
This study was designed to assess the impact of introducing a new, transferable, actionable anticipatory care plan across all healthcare settings in the Southland Region of New Zealand. To our knowledge, no other studies have assessed the impact of such a document in New Zealand. Results indicated that the COAST form is acceptable to health professionals, patients, and families, compared with usual standard practice. The project rapidly became well integrated in clinical practice, in part due to it being a ground-up initiative developed by clinicians who work regularly with seriously ill and dying patients in multiple settings, and with input from others who work with this population. Education of junior doctors and other staff about the importance of having discussions to explore patient wishes and treatment goals, and providing care that is medically appropriate and goal-directed, has been crucial in embedding the COAST process. Quantitative data collection showed that the implementation of COAST forms correlated with reduced hospital admissions and emergency department presentations; those findings are outside the scope of this paper but have been published elsewhere.<sup>7</sup>

The initial stakeholders' meeting demonstrated widespread support within the local area, and following the pilot, every rest home and hospital in Southland continue to support and honour COAST forms within their setting. The success of the initiative is further demonstrated by the fact that at the end of the pilot, ambulance crews and staff within the emergency department continued to support the initiative and proactively asked patients if they had a COAST form.

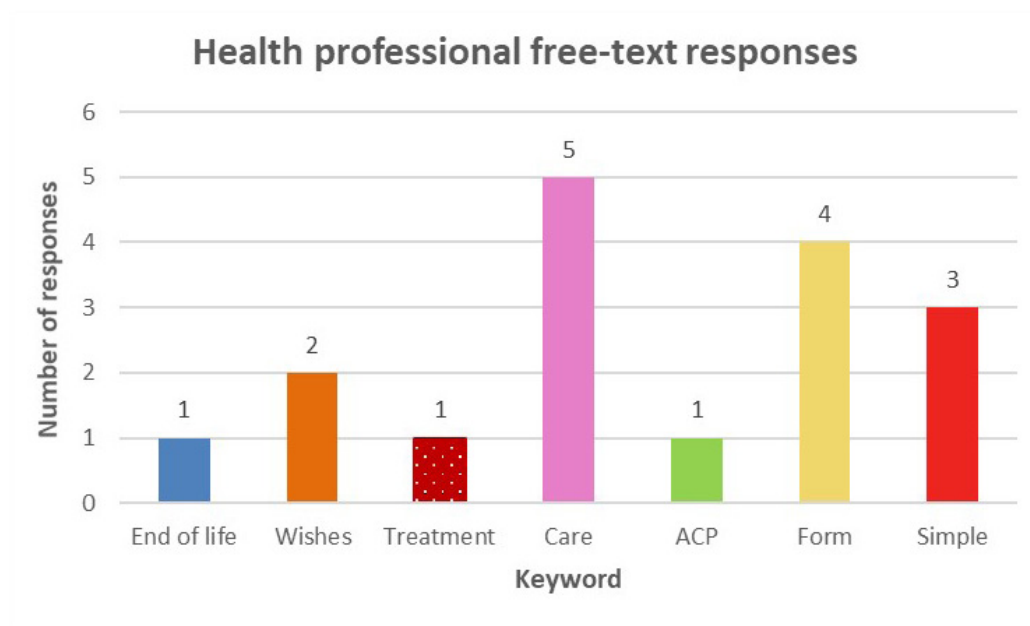
A limitation of the study is that the response rates for patient and health professional surveys were low, at 20% and 27% respectively. This is a challenge that is well described in the literature, and our response rates are comparative with response rates of other palliative care studies.<sup>8,9</sup> The low patient survey response rate could be explained by the significant number of deaths in the participant group during the study period. The survey comments that were received were generally positive and supportive of the initiative.

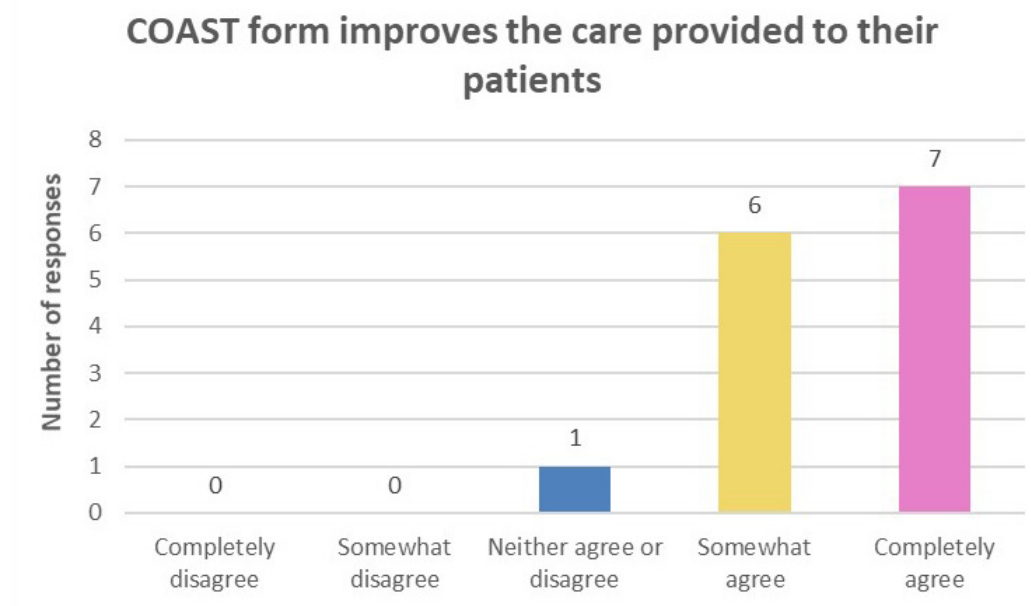
The COAST form was updated in response

**Figure 1:** Keywords in patient free-text responses to COAST survey.



**Figure 2:** Practitioner free-text comments to COAST survey.



**Figure 3:** Perceived improvement in patient care.

to valuable feedback obtained at the initial stakeholders' meeting, feedback from the COAST Steering Committee, and survey comments. As the COAST form and process has been so well-received in the region, our hope is that an electronic COAST form—or a straightforward, universally-accepted document similar to COAST—can be developed at the regional or national level. IT and graphic design expertise would be beneficial, as such support could enhance the visual appeal of the form and allow it to be electronically completed, saved, reviewed, updated, printed, and disseminated to involved parties including rest homes, primary care, partner health agencies, ambulance personnel, and patients.

There was a further survey comment suggesting that the patient should sign the COAST form. This idea was discussed and debated extensively in the study design period, with the conclusion that as the COAST form is a medical order, a patient signature is not appropriate. The clinician who completes the COAST form is required to record the date of the relevant discussion with the patient or surrogate decision maker, and the original form stays with the patient. COAST education for patients and providers was clear that COAST forms were only

to be completed with the approval of the patient or surrogate and only after the appropriate discussion took place. Patients or surrogate decision makers have the right to revoke a COAST form at any time. For the purposes of this study, patients did have to sign a consent form to be recruited.

Advance care planning has been associated with higher levels of patient and family satisfaction,<sup>2</sup> so it may be useful to assess whether having a COAST form has any psychological impact for patients; there may be benefits to patients having healthcare teams aware of their wishes and ceiling of treatment without the need for repeated discussions and multiple forms. This could be assessed using a validated quality of life tool, such as the EORTC QLQ-C30.<sup>10</sup>

## Conclusion

Implementation of the COAST form has been widely accepted by patients, families, and health professionals alike. Health professionals within the Southland DHB continue to strongly support the project, with over 1,000 COAST forms completed to date. Our hope is that the project could be rolled out on a national basis.

**COMPETING INTERESTS**

Nil.

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Appendix 1: COAST form.


**Completed and signed directive valid across all health encounters and settings**



**Southern District Health Board**  
Piki Te Ora



**COAST**  
CLINICAL ORDER ARTICULATING SCOPE OF TREATMENT  
Huarahi Rangimārie



**hospice southland**  
*Living every moment*

**Patient's label or details:**

Name:  NHI:  D.O.B:

Address:  GP Name:

Resuscitation Status	Medical interventions
<input type="checkbox"/> <b>FOR</b> resuscitation <small>Attempt CPR. (must tick FULL TREATMENT box)</small>	<input type="checkbox"/> <b>Full Treatment</b> <small>Prolongation of life by all usual and available means including intubation, non-invasive ventilation, ICU, DC cardioversion.</small>
<input type="checkbox"/> <b>DO NOT</b> resuscitate <small>(Eligible for any medical interventions option)</small>	<input type="checkbox"/> <b>Selective Treatment</b> <small>Treat medical conditions but avoiding medically inappropriate interventions or measures unwanted by patient. Examples include non-invasive ventilation, trial DC cardioversion, antibiotics. Transfer to hospital if care needs unable to be met in community</small>
<input type="checkbox"/> <b>Comfort-Focused Treatment</b> <small>Relieve pain and suffering with medication by any route necessary and available, not for prolongation of life; use oxygen, suctioning and manual treatment of airway obstruction. Do not use above options unless consistent with comfort goals. DO NOT transfer to hospital unless needs unable to be met in community.</small>	<input type="checkbox"/> All artificial nutritional & fluid support <input type="checkbox"/> Supplemental fluids e.g. IV or SC <input type="checkbox"/> Oral fluid/food for comfort only <input type="checkbox"/> Mouth care only. Justification: <input type="text"/> <small>Food and fluids always to be offered by mouth if possible.</small>
<b>Fluid and Nutrition</b>	<b>Medical/Cultural/Spiritual considerations</b> <input type="text"/>
<b>Additional considerations / clarifications of medical interventions</b>	<input type="text"/>
<b>I have discussed this with:</b> Name: <input type="text"/> Date: <input type="text"/>	<input type="checkbox"/> Patient <input type="checkbox"/> Activated EPOA <input type="checkbox"/> Welfare Guardian <input type="checkbox"/> Other (specify): <input type="text"/>
<b>Signature of Doctor / Nurse practitioner</b> <small>My signature below indicates to the best of my knowledge the above directive is consistent with the patient's preferences and medical conditions.</small>	
Name: <input type="text"/>	Signature: <input type="text"/>
Position: <input type="text"/>	Date: <input type="text"/>

Appendix 2: Pre-implementation questionnaire for healthcare professionals.

### COAST STAKEHOLDERS MEETING FEEDBACK

1. Please identify the capacity in which you attended this meeting (please circle):

Patient/Professional (please indicate job title): \_\_\_\_\_

2. Do you have experience with Advanced Care Planning?	Yes	No
	<input type="checkbox"/>	<input type="checkbox"/>
Comments:		

3. Do you view a Not for Resuscitation (NFR) form as being different from an Advanced Care Plan?	Yes	No
	<input type="checkbox"/>	<input type="checkbox"/>

4. Do you think the introduction of COAST form would be beneficial to you?	Yes	No
	<input type="checkbox"/>	<input type="checkbox"/>
Comments:		

5. Do you have any ideas on how the COAST form could be improved?	Yes	No
	<input type="checkbox"/>	<input type="checkbox"/>
Comments:		

6. What barriers do you perceive to COAST form implementation?

7. What education or training about the COAST form/process would you require if the COAST form were to be introduced?

8. What other thoughts do you have about the COAST form or about advance care planning in general?

Appendix 3: Post-implementation questionnaire for patients/proxy decision makers.



Please complete this survey and return in the pre-paid addressed envelope to Hospice Southland



**POST-COAST SURVEY QUESTIONS FOR PATIENTS/PROXY DECISION MAKERS**

Relationship of person completing survey (please tick):

Patient  Activated EPOA  Welfare Guardian  Other  (specify) \_\_\_\_\_

Are you familiar with the idea of advance care planning (ACP)?	Yes	No

Have you completed a written advance care plan (ACP) document?	Yes	No	Unsure

Have you talked with someone you trust - like a family member or friend - or with your Enduring Power of Attorney (EPOA) about what treatments you would or wouldn't want if you are seriously ill or dying?	Yes	No
Comment:		

Have you and your doctor talked about what treatments you would or wouldn't want if you are seriously ill or dying?	Yes	No
Comment:		

Are you familiar with the COAST form?	Yes	No	Unsure

As far as you know, what is the purpose of the COAST form?

Do you have a completed COAST form for yourself or someone you care about?		
Yes, for myself	Yes, for someone else (please specify)	No

Appendix 3 (continued): Post-implementation questionnaire for patients/proxy decision makers.



Please complete this survey and return in the pre-paid addressed envelope to Hospice Southland



If you or someone you care about has a COAST form, how well was COAST explained to you?				
No discussion with me at all	Not explained well	Explained well	I do not recall	Does not apply (No COAST form)

Were you in agreement with having a COAST form in place for yourself or the person you care about?	Yes	No
Why or why not? Comment:		

If you or someone you care about has a COAST form, how has this affected your/that person's health care?					
Made care a lot worse	Made care somewhat worse	No difference to care	Made care somewhat better	Made care a lot better	Does not apply (No COAST form)

What concerns do you have about the COAST form or process?

How could the COAST form and process be improved?

What else would you like us to know?

Appendix 4: Post-implementation questionnaire for healthcare professionals.

### POST-COAST SURVEY QUESTIONS FOR PROVIDERS

<b>What do you know about the COAST form and process?</b>

<b>How many of your patients/clients have had a completed COAST form?</b>	<b>None</b>	<b>A few (1-3)</b>	<b>Several (4-9)</b>	<b>More than 10</b>

<b>Did you receive adequate education and training about the COAST form and process?</b>	<b>Yes</b>	<b>No</b>
<b>Comment:</b>		

<b>What works well about the COAST form and process?</b>

<b>How much do you agree with the following statement: The COAST form improves the care provided to my patients/clients?</b>				
<b>Completely disagree</b>	<b>Somewhat disagree</b>	<b>Neither agree or disagree</b>	<b>Somewhat agree</b>	<b>Completely agree</b>

<b>What barriers are there to COAST form completion?</b>

Appendix 4 (continued): Post-implementation questionnaire for healthcare professionals.



<b>What barriers are there to COAST form implementation?</b>

<b>How comfortable are you completing the COAST form?</b>		
<b>Not at all comfortable</b>	<b>Somewhat comfortable</b>	<b>Very comfortable</b>

<b>How comfortable are you following the COAST form orders if you yourself did not complete and sign the form?</b>		
<b>Not at all comfortable</b>	<b>Somewhat comfortable</b>	<b>Very comfortable</b>

<b>How could the COAST form be improved?</b>

<b>What other thoughts do you have about the COAST form or about advance care planning in general?</b>