THE COAST FORM

A clinical tool designed to improve end of life care for patients across all settings

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A bit about us

- Amanda is the medical director and palliative specialist for Hospice Southland
- Yih Harng is a consultant geriatrician in Palmerston North (previously Southland Hospital)
- Kylie is a consultant medicine physician with Southland Hospital
- Laura is a former medical officer with Hospice Southland
- Lisa is a palliative care nurse specialist (PCNS) who works for Hospice Southland in aged residential care

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A bit of background

- In 2017-2018, Hospice Southland completed a pilot initiative in which complex patients in rest homes received either a proactive assessment by a palliative care nurse specialist (PCNS) or usual facility care

- Although not a primary focus of the initiative, we found several examples of patients who had
  - No advance care plan (ACP)
  - Fragmented ACP
  - ACP that was not honoured across all treatment settings

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Sample case - HK

- HK was hospitalised 5 times in the year before enrolling in the pilot initiative
- PCNS worked with HK, family, the ARC facility, and the GP to develop an ACP and document it in the ARC record
  - Wish to NOT be transferred to hospital explicitly recorded
  - GP left contact details with instructions to contact her first before sending to hospital
  - All comfort meds prescribed and available
- Within days of this, she was sent to ED by the weekend nurse – no GP contact
- ED doctor wrote in the discharge summary that HK "would benefit from palliative care involvement in the community" and ACP

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Sample case - HK

- What went wrong?
- What could possibly have been done to avoid the hospital transfer?
- This case represents a systems failure
- Unfortunately, not an isolated incident

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Advanced Care Planning

- By definition, ACP is an individualised process of discussion and shared planning for future health care

- Considerable investment in and promotion of advance care planning discussions and ACP document completion for all patients at the national, regional, and local levels
  - “My Advance Care Plan & Guide” is holistic and comprehensive
  - Articulates patient wishes quite well
  - The document is 14 pages long

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ACP – page 10

6 My treatment and care choices

This section is best completed with help from a doctor, nurse or specialist.

There are medical procedures that keep you alive or delay death. These may include resuscitation (CPR), life support, getting food and drink through a tube, and kidney dialysis.

Sometimes treatments can be both helpful and harmful. They may keep you alive, but not conscious, or make you a bit better for a short time, but cause you pain.

You need to decide if this is what you want. Your healthcare team will only offer treatments that you will benefit from, this includes the offer of CPR.

Think about what is important to you. For example, quality of life (how good your life is) or quantity of life (how long your life is)?

Are there circumstances in which you would want to stop being kept alive and be made comfortable so you can have a natural death?

If I am seriously ill and I am unable to make decisions for myself, the following best describes the care I would like to receive. I understand this does not require the healthcare team to provide treatments which will not be of benefit to me.

Seriously ill to me means:

_____

_____

_____

Choose only ONE of these five options.

1 I would like my treatment to be aimed at keeping me alive as long as possible. I wish to receive all treatments that the healthcare team think are appropriate to my situation.
The exceptions to this would be:

_____

If required and appropriate I would want CPR to be attempted:

○ YES ○ NO ○ I will let my doctor decide at the time.

2 I would like my treatment to focus on quality of life.
If my health deteriorated I would like to be assessed and given any tests and treatments that may help me to recover and regain my quality of life, but I DO NOT WANT TO BE RESUSCITATED.
For me, quality of life is:

_____

3 I would like to receive only those treatments which look after my comfort and dignity rather than treatments which try to prolong my life. I DO NOT WANT TO BE RESUSCITATED.

4 I cannot decide at this point. I would like the healthcare team caring for me to make decisions on my behalf at the time, taking into account what matters to me and in close consultation with the people I have listed in Section 4.

5 None of these represent my wishes.
What I want is recorded in my Advance Directive on page 11.

I choose Option Number: _____

ACP – page 11

6 My Advance Directive

If you have treatment and care preferences for specific circumstances or you want an advance directive please write the details below.

An advance directive is a way of choosing beforehand specific treatments you would or would not want in different circumstances if you were no longer able to speak for yourself.

If you can't speak for yourself, it is the responsibility of your healthcare team to apply your advance care plan and any advance directive. When applying the advance directive, they must be confident that you:

(1) fully understood what you were asking for;

(2) were free from influence or duress from someone else, and

(3) meant this to apply to the current situation.

In the following circumstances:	I would like my care to focus on:	I would accept the following treatments:	I would wish to refuse or stop the following treatment:
Example: Severe stroke, unable to recognise anyone	*Example: Allowing a natural death*	*Example: Comfort measures*	*Example: Artificial feeding*

○ If I have left this section blank, I am happy with the choice I made on the previous page and have no other preferences.

Current use of ACP in practice

- Recommended for ALL patients
- Can be challenging to apply ACP to clinical practice, *especially in the final year of life* when patients typically have
  - More symptoms
  - Increased physical care needs
  - Increased medical complexity
  - Potential deterioration in or loss of medical decision making capacity
  - More frequent transitions across care environments
- Not all clinical issues can be foreseen in an ACP

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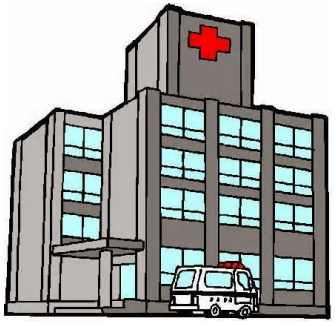

How do we currently translate ACP into local clinical practice?

Current application of ACP in Southland

- Facilities, departments, and agencies have come up with a variety of ways to translate ACP into actionable clinical plans
  - Orange NFR stickers, and ceiling of care forms in hospital
  - Orange NFR stickers, ambulance letters in hospice
  - Each ARC facility/corporation has its own process and forms
  - GPs have their own processes for documenting ACP discussions and care plans
  - St John protocols

- Each plan is (usually) valid and honoured in its primary location, but not across all settings
  - New care environment → New process and forms

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Consequences for EOL care

- Potential for unhelpful, unwanted, or burdensome
  - Medical treatments
  - Transfers
  - Hospitalisations
- Time spent following various facility-specific processes and filling out multiple forms
- Confusion and poor handovers of care
  - After hours, on call, substitute providers
- Patients/families perceive that care is fragmented
  - Why are we being asked this again?
  - Don't they read my records?
  - Maybe I made the wrong decision if I'm being asked over and over..

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What we thought was needed

- After working and caring for seriously ill and dying patients in various locations, reviewing published studies, and speaking with various care providers (including a Nov 2018 stakeholders' meeting)
  - Hospital doctors and nurses
  - GPs and practice nurses
  - District nurses
  - Palliative care and hospice nurses
  - Rest home nurses and administrators
  - St John personnel
  - WellSouth Quality Committee
  - Palliative specialists
  - Legal advice
- Need for a definitive document that *quickly* and *concisely articulates* and *communicates* the scope of treatment for complex or terminally ill patients *in every care setting*

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What is being done already?

- **POLST** in USA
  - Developed in Oregon in 1990s
  - For patients whose medical providers would not be surprised if they died in the next year
  - Now in most states, many with e-registries

- **Goals of Care** in Australia
  - Introduced at Royal Hobart Hospital in Tasmania in 2011
  - Now used at Northern Health in Melbourne as well
  - Stratifies patient into one of 3 phases:

    * Curative/Restorative * Palliative * Terminal

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NEVADA POLST (Physician Order for Life-Sustaining Treatment)

HIPAA PERMITS DISCLOSURE TO HEALTH CARE PROFESSIONALS & ELECTRONIC REGISTRY

Faxed, copied or electronic versions of a Nevada POLST are legal and valid

SIDE 1: Medical Orders

Consult this form when patient lacks decisional capacity. It is intended to be honored by any health-care provider who treats the patient in any health-care setting, including, without limitation, a residence, health care facility or the scene of a medical emergency (NRS 449.694.). A section not completed does not invalidate the rest and indicates full treatment for that section.

Last Name/First/Middle Initial		
Date of Birth (dd/mm/yr)	Last 4 SSN	Gender
/ /		M F

Section A CPR Check one only

CARDIOPULMONARY RESUSCITATION (CPR). *Patient/resident has no pulse & is not breathing.*

☐ Attempt Resuscitation (CPR) (See Section B: Full Treatment required)

☐ Allow Natural Death (Do Not Attempt Resuscitation) If available, EMS-DNR #:_____

When not in cardiopulmonary arrest follow orders in Section B

Section B Interventions

MEDICAL INTERVENTIONS. *Patient/resident has pulse and/or is breathing.*

Life-sustaining treatment may be ordered for a trial period to determine if there is benefit to the patient. If a life-sustaining treatment is started, but turns out not to be helpful, the treatment can be stopped.

1. ☐ **Comfort Measures Only.** The patient/resident is treated with dignity, respect and kept clean, warm and dry. Reasonable measures are made to offer food and fluids by mouth as tolerated, and attention is paid to hygiene. Medication, positioning, wound care and other measures are used to relieve pain and suffering. Oxygen, suction and manual treatment of airway obstruction may be used as needed for comfort. These measures are to be used where the patient/resident lives. Transfer only if comfort needs cannot be met in current location.

*Other Instructions:*_____

2. Limited Medical Interventions. Comfort measures always provided.

a. Life-Sustaining Antibiotics.

☐ No antibiotics. Use other measures to relieve symptoms
☐ Administer antibiotics by mouth as necessary
☐ Administer antibiotics IV as necessary

*Other Instructions:*_____

b. Artificially Administered Fluids and Nutrition.

☐ No feeding tube
☐ Defined trial period of feeding tube
☐ Long term feeding tube
☐ No IV fluids
☐ Defined trial period of IV fluids
☐ Long term IV fluids

*Other Instructions:*_____

c. Other Limitations of Medical Interventions.

☐ No intensive care admission
☐ No x-ray
☐ No IV (assure agreement with **a.** & **b.** above)
☐ No hyperalimentation
☐ No electrolyte or acid/base corrective measures
☐ No lab work
☐ No antiarrhythmic drugs
☐ No dialysis

*Other Instructions:*_____

3. ☐ **Full Treatment.** Includes care above plus endotracheal intubation and cardioversion.

*Additional Instructions:*_____

Section C Physician Signature

Date **(Required)**	Physician Signature **(Required)**	Physician Name (Print)
Physician Office Address	Physician Phone	Physician License No.

Send original with patient when discharged or transferred

Data to support this concept

- **POLST**
  - Patients in WV with cancer and POLST more likely to die out of hospital (85.7%) than patients with ACP alone (72%) even though prognosis was shorter and POLST was done later than ACP
    (Pedraza et al, 2017)
    - ACP did not improve EOL quality metrics
    - No benefit to having both ACP and POLST
    - POLST patients more than twice as likely to use hospice programme
  - Growing evidence that POLST supports autonomy, improves communication, minimises unwanted interventions, decreases EOL costs, simplifies decision making, and eases transfers between care providers and institutions
    (example: Brugger et al, 2013)

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Data to support this concept

- **Goals of Care** in Australia – better than NFR alone
  - Trial on 1 hospital ward
  - 34% of admitted patients had an NFR form prior to the initiative
  - GOC completed for 75% after initiative introduced
  - Safe, effective, no complaints or reportable incidents, and improved recognition of dying process
  - Now expanded and growing evidence to support its use

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What is being done currently in NZ?

- Much variability within and across DHBs
  - Pilot use of a 2 page “Options for Treatment and Resuscitation” (OtTER) form in Nelson Marlborough
  - Canterbury DHB developed a 2 page DNACPR order that incorporates free text fields to record any additional diagnostic/treatment preferences, rationale for the decision, and details of the pertinent discussion(s)
    - Also an 8 page medical care guidance plan document
  - Both are acute hospital initiatives that haven’t been incorporated into the outpatient or ARC setting

- To our knowledge, no current plan to develop a universal and portable clinical orders document at the national level

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This is where COAST comes in….

- Project title: Introducing and implementing a transferable, readily accessible, and actionable end of life planning tool for patients with advanced serious illness or frailty in southern New Zealand

- To trial a POLST-inspired document adapted to the Southland region
  - Clinical Order Articulating Scope of Treatment (“COAST”) form
  - Maori term written on form: *Huarahi Rangimārie*
    (translates to “Peaceful Path”)

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- This project is designed to enhance and streamline processes already in place
- There are no attempts to influence the discussions between patients/proxies and clinicians, or to influence the clinical decision making
- Limit initially to adults deemed to be in their final year of life as evidenced by the “Surprise Question”
  - *“Would you be surprised if this patient died in the next 12 months?”*

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Proposal

- Determine if such a document is feasible and acceptable within the Southland region
- Identify factors that may facilitate wider implementation of COAST across the district
  - Work out the kinks in a small network before formally adopting on a broader scale
- Our prediction is that COAST will be well accepted by patients and health professionals, and will actually reduce hospitalisations in the last year of life

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How is COAST different from ACP?

Advance Care Plan (ACP)	COAST
Any stage of health or illness	Seriously ill, thought to be in final year of life
Must have capacity to do ACP	Capacity not required
Communicates patient preferences	Medical order generated after discussion with patient/proxy
Variable forms, documentation, and implementation	Standardised
Similar concept to the discussion a provider has with a patient about risks/benefits/goals of medication use	Similar to a prescription generated after the discussion about a medication – like a prescription, COAST is a tool for health professionals to communicate

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COAST eligibility and process

1. **Identify eligible patients**
   - Age 18+
   - Doctor/NP would not be surprised if the patient is in the last year of life
   - Patient or proxy agrees to have a COAST form
2. **Clinician completes COAST form** following usual discussion about resuscitation status/ceiling of treatment
3. **Patient/family given COAST packet** with information sheets and a survey
4. Written **consent** from patient in order to participate in the research part of COAST
   - Collect demographic data, number of presentations to hospital before and after COAST, place of death if applicable
   - If patient is not competent, he/she can participate in the research if clinician deems it to be in their best interest
5. At the end of each phase all participating clinicians invited to provide feedback on COAST via **questionnaire**

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Timeline

1. Background research, consultation, develop of COAST form, peer review ☑ August-December 2018
2. HDEC approval ☑ March 2019
3. Educate doctors/NPs about COAST ☑ March 2019
4. Implement COAST in 3 phases with on-going data collection ☐ May 2019 – January 2020
5. Measurement of hospitalisations 12 months before and after implementation of forms ☐ August 2019 – January 2021

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COAST implementation

- **Phase 1** (May through July 2019)
  - Southland Hospital, Hospice Southland, Palliative Care Advisory Service
- **Phase 2** (August through October 2019)
  - Expand to GPs and ARC facilities in Invercargill
- **Phase 3** (November 2019 through January 2020)
  - Expand to Southland region

- Education on wards, ARC, St John, primary care provided by research team
- Steering Committee meets prior to beginning each phase
- Follow up stakeholder meeting planned to report on COAST initiative findings after 12 months (roughly April 2020)

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Completed and signed directive valid across all health encounters and settings

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Huarahi Rangimārie

Clinical Order Articulating Scope of Treatment

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Patient's Label or details:

Name/NHI/DOB/Address/GP name

Resuscitation status	Medical Interventions
☐ **FOR** resuscitation Attempt CPR. (Must tick FULL TREATMENT box)	☐ **Full Treatment** Prolongation of life by all usual and available means including intubation, non-invasive ventilation, ICU, DC cardioversion.
☐ **DO NOT** resuscitate (Eligible for any medical interventions option)	☐ **Selective Treatment** 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.
	☐ **Comfort-Focused Treatment** 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.
Fluid and nutrition	❑ All artificial nutritional & fluid support ❑ Supplemental fluids e.g. IV or SC ❑ Oral fluid/food for comfort only ❑ Mouth care only. Justification:…… *Food and fluids always to be offered by mouth if possible.*
Additional considerations/ clarification of medical interventions	Medical/Cultural/Spiritual considerations Free text

I have discussed this with:		
Name:……	❑ Patient ❑ Activated EPOA ❑ Welfare guardian ❑ Other (specify): ……	Date:……

Signature of doctor / nurse practitioner

My signature below indicates to the best of my knowledge the above directive is consistent with the patient's preferences and medical conditions

Name:……	Signature:……
Position:……	Date:……

FAQs

1. Great idea. Who is going to do the work?
   - Clinical investigators project managing
   - Study co-ordinator funded by Hospice Southland
   - House officers, medical students, summer research student to help with data collection

2. How will each agency access and use COAST?
   - Original form stays with patient wherever patient goes
   - Working with IT to create a flag and location in Health Connect South (hospital electronic record)
   - Study coordinators and clinical leads available to work with agencies to ensure COAST readily accessible to all who provide care

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FAQs

3. Who is paying for this?
   - Use existing FTE for hospice/DHB study investigators.
   - Hospice employing 0.4 FTE nurse as study co-ordinator.
   - Will seek innovation funding and grant support – one successful application so far (ONE Foundation)

4. What if agencies have their own process?
   - We ask that COAST be done along with or instead of those processes so that communication is standard and streamlined during the pilot period
   - The goal is to give patients and their families end of life care that is well coordinated, goal directed, and of the highest quality in ALL locations
   - The doctor/NP still needs to document the discussion and providers need to have a high level of TRUST in one another
   - May not be honoured outside of Southland – encourage patients to bring COAST with them as a starting point if they seek care

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FAQs

5. Does COAST expire? Also, what if treatment plans or goals change?
   - No, COAST does not expire.
   - If goals change, then the old COAST is voided out and a new COAST form is created.
   - The valid COAST is the most recent COAST and we work to ensure that the up to date COAST is available to care providers.

6. What if the patient/proxy doesn't want a COAST or doesn't consent to the research?
   - The COAST form is a medical order. Patients with decision making capacity can decline to have treatments including COAST (just as some decline to address code status or ceiling of care).
   - If a patient with capacity does not consent to the research part of COAST, we cannot collect or analyse COAST data for that patient.

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FAQs

7. Should the COAST form be reviewed?
   - The COAST form does not have an expiration date. COAST form should be reviewed periodically and updated as appropriate if:
     - There is a significant change in an individual's health status, or
     - The individual's treatment preferences change

8. Does the COAST form replace Advanced Care Planning?
   - No, the COAST form is meant to complement Advanced Care Planning.
   - If COAST form orders directly conflict with orders stated in a patient's Advanced Care Plan, the most recent document takes precedence.

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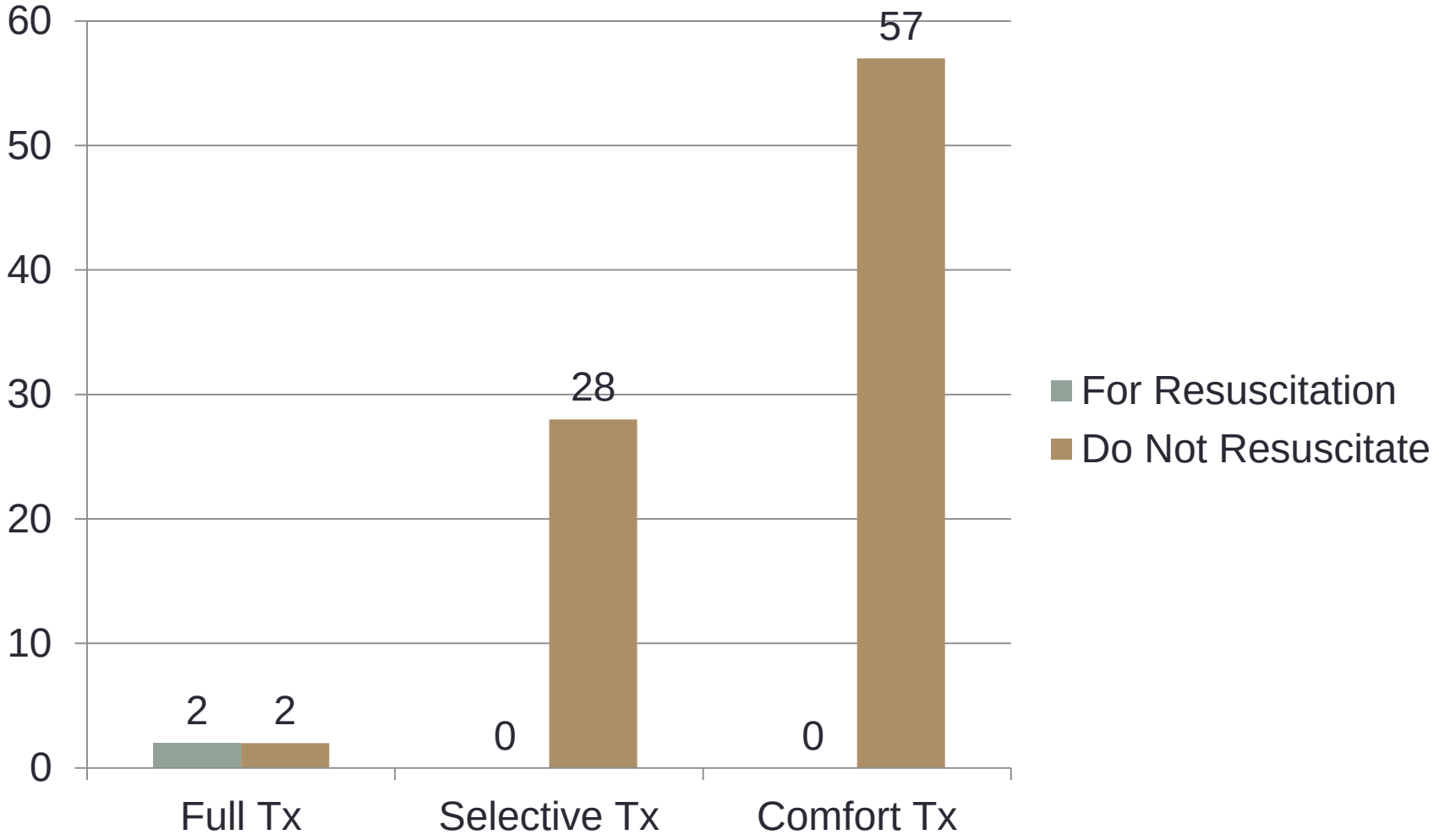
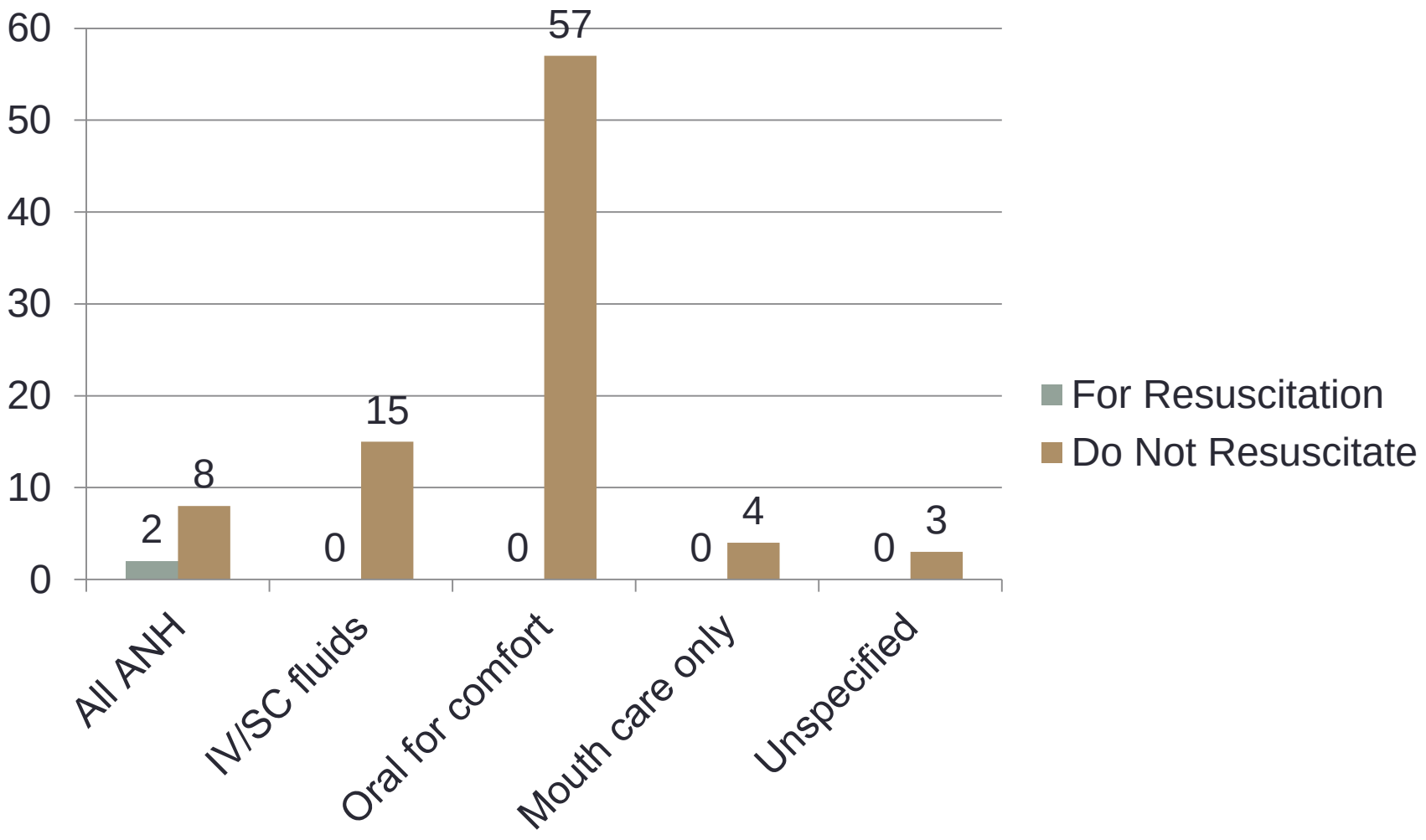
Preliminary Data (N = 89)



Fluid and Nutrition



Preliminary Data

- **Updated COAST forms** (N = 2)
  - One DNR changed from selective to comfort-focused treatment
  - One For Resuscitation changed to DNR with comfort-focused treatment

- **Who is completing COAST forms?**
  - 34 done by hospital doctors (38.2%)
  - 50 done by hospice doctors (56.2%)
  - 5 done by GPs (5.6%)

- **3 missing research consent**

COAST successes (so far)

- **Clinicians, hospital wards, St Johns, and ARC facilities all enthusiastic and supportive of the trial**
  - ED consultants asking patients/families if they have COAST
  - A few patients have proactively asked for a COAST form
  - St Johns looking for COAST forms in homes
  - Rural GPs and hospitals asking when they get to start doing COAST
- **Clinicians and patients like that the form transfers across all settings**
- **Prompts health providers to put comfort medications in place if a patient is for "Comfort-Focused Treatment"**

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Patient/proxy survey feedback (so far)

- **As far as you know, what is the purpose of the COAST form?**
  - "To stop having the same conversation"
  - "Lets me have a choice of what happens when the time comes – my decisions count"
  - "To know what to do with me"
  - "So that everybody that is involved in my care are on the 'same page' and understand what I need to remain comfortable + pain free"

- **What concerns to you have about the COAST form or process?**
  - "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"

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COAST challenges so far

- **Some wards not able to make colour copies of COAST**
  - Changed hospice fax paper colour to match the colour of the COAST form
  - Tried a triplicate form but can barely read the bottom copy
    - Useful, though, when COAST done in a home as can leave the original there with the patient
  - Can scan form and securely email to study coordinator

- **1 COAST form done in hospital without patient/family knowledge**
  - The form was not sent to the study coordinator so found out when the ARC facility brought it to our attention
  - Voided

- **Difficulty getting into some GP practices to do education**
  - Developing a brief training video

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COAST challenges so far

- **Clinician selecting "Mouth care only" with no written justification** (2 so far) **or not filling in Fluid and Nutrition section** (3 so far)

- **Concern that the discussions clinicians have about COAST and ceiling of treatment are not always robust**
  - Does not seem to be unique to COAST form
  - Much education has had to focus on how to have discussions about ceiling of treatment with patients

- **Delays getting COAST into Health Connect South**

- **Poor clinician survey response rate** (2 from Phase 1)

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Questions?

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www.coastform.net

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