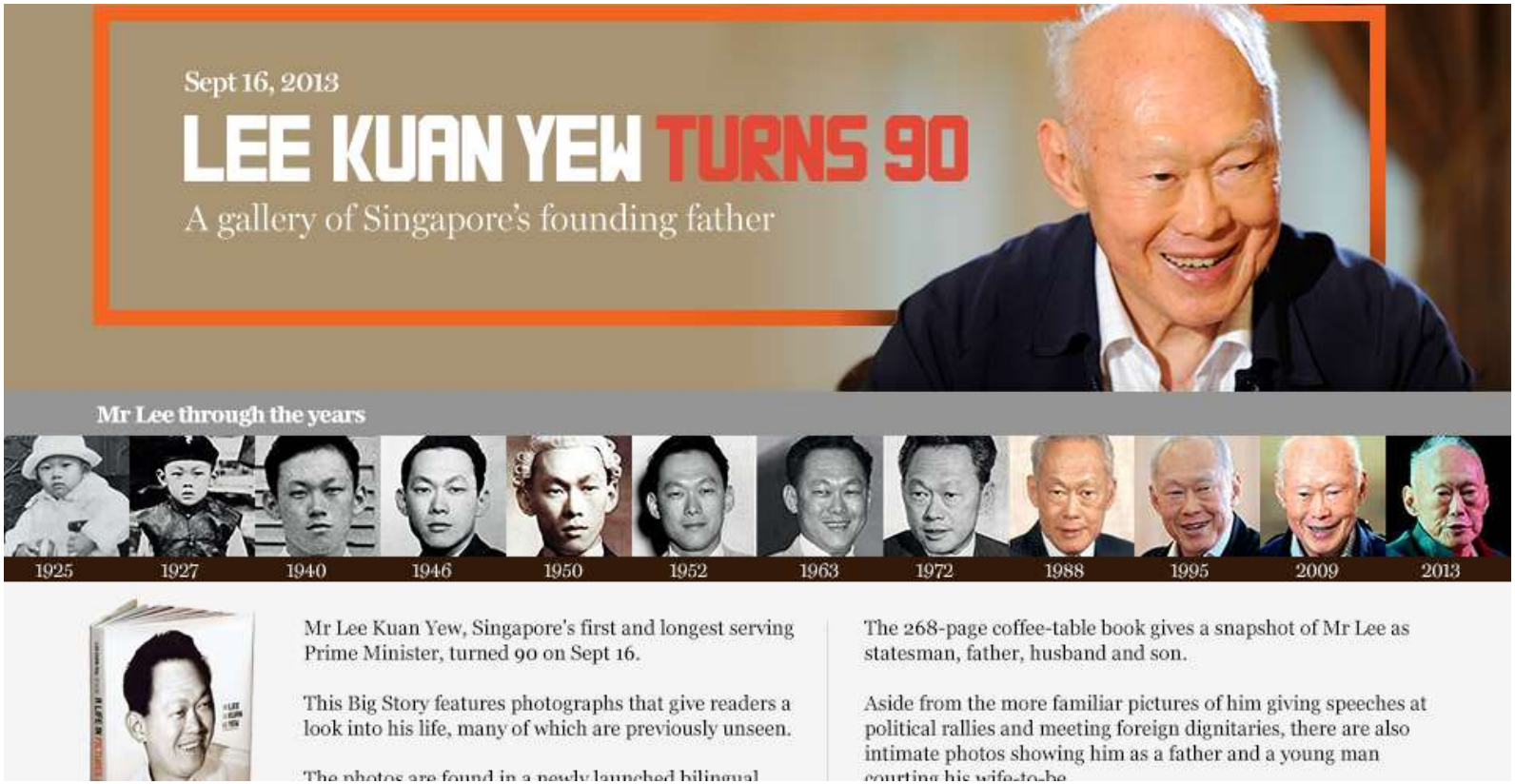
# ADVANCE DIRECTIVE: MORE THAN A FORM

Dr Angel Lee
Senior Consultant
Tan Tock Seng Hospital
Dover Park Hospice


Every Moment Matters




**"Some time back, I had an Advanced Medical Directive (AMD) done which says that if I have to be fed by a tube, and it is unlikely that I would ever be able to recover and walk about, my doctors are to remove the tube and allow me to make a quick exit."**

**Lee Kuan Yew**
**"One Man's View of the World"**

Advance Medical Directive Act enacted in parliament in 1996. Revised 1997.

THE ADVANCE MEDICAL DIRECTIVE ACT 1996 [ACT 16 OF 1996, SECTION 3]

THE ADVANCE MEDICAL DIRECTIVE REGULATIONS 1997

(This form may take you 5 minutes to fill in)

## PERSON MAKING THE ADVANCE MEDICAL DIRECTIVE

Name:

NRIC No.: - - Sex: Male Female (please tick)

Date of Birth: - - (must be at least 21 years of age)
Day Month Year

Address:

Singapore

Home Telephone: Office Telephone:

## THE DIRECTIVE

1. I hereby make this advance medical directive that if I should suffer from a terminal illness and if I should become unconscious or incapable of exercising rational judgment so that I am unable to communicate my wishes to my doctor, no extraordinary life-sustaining treatment should be applied or given to me.

2. I understand that "terminal illness" in the Advance Medical Directive Act 1996 means an incurable

# Terminology in Singapore's AMD (1997)

- "terminal illness"
  - An incurable condition caused by injury or disease from which there is **no reasonable prospect of a temporary or permanent recovery**, where
  - (a) **death** would, within reasonable medical judgement, be **imminent** regardless of the application of extraordinary life sustaining treatment and
  - (b) the application of extraordinary life sustaining treatment would only serve to **postpone the moment of death** of the patient

# Terminology in Singapore's AMD

- "extraordinary life-sustaining treatment"
  - Any medical procedure or measure which, when administered to a terminally ill patient, will only **prolong the process of dying** when death is imminent, but excludes palliative care.
- "palliative care"
  - (a) the provision of **reasonable** medical procedures for the **relief of pain, suffering or discomfort** and
  - (b) the **reasonable provision of food and water**

- Advance life sustaining treatment
  - Mechanical ventilation
  - Renal dialysis

- Basic life sustaining treatment
  - “Provision of food and water”
  - Oxygen

- Advance or Basic?
  - Intravenous Drips
  - Total Parenteral Nutrition
  - Antibiotics for the treatment of infections

# Life sustaining treatment

- Made when one is still well
- Indicate preferences with regards to treatment at EOL
- Effected when one is terminally ill and no longer able to make own decisions
- **Written form**, may be revoked
- **Legally recognised** within the country
- Proxy directive that allows for surrogate decision making

# Advance Medical Directive (AMD) in Singapore

**"A person of sound mind who has attained the age of 21 years…"**

## Signing

- 2 witnesses (one must be a doctor)
- Prescribed form, which will be lodged with registry
- May revoke anytime orally or in writing

## Searching

- Patient is terminally ill and is incompetent
- Requires life-sustaining measures
- Doctor informs registry using prescribed form
- Registry confirms that an AMD is in force

## Enactment

- A panel of 3 doctors must certify (at least 2 specialist)
- Unanimous decision
- If not unanimous, a second panel of 3 doctors will be appointed

- Since 1996,
  - 15,000 have signed up for the AMD.
    - 0.04% of population
    - 0.02% in Australia
    - 20% in USA

# How useful is the AMD in Singapore?

- Since 1996,
  - To our knowledge, there has only been 6 searches for the AMD resulting in its application.
  - In fact, there has been at least 19 revocations of the AMD

# How useful is the AMD in Singapore?

Original Article

# Knowledge, Attitudes and Practices of the Advance Medical Directive in a Residential Estate in Singapore

Matthew Tay,[1] Sin Eng Chia,[2] MD, Judy Sng,[2] MMed (Occup Med)

**Abstract**

**Introduction: This study investigates the knowledge, attitudes and practices of residents in a residential estate in Singapore on the Advance Medical Directive (AMD). Materials and Methods: A community-based cross-sectional study was conducted with residents in the residential**

Only **37.9%** of residents knew about the AMD before the study… There is a need to **increase awareness** of the AMD. Public education…

**and accepted the "imminence of death" were found to correlate signi cantly with the willingness to sign an AMD [Prevalence Rate Ratio (PRR) = 2.050 [1.140-3.685], *P* = 0.016; PRR = 2.669 [1.449-4.917], *P* = 0.02, respectively]. Conclusions: There is a need to increase awareness on the AMD. Public education methods can be improved to inform residents on the implications of the AMD.**

**Ann Acad Med Singapore 2010;39:424-8**

- By definition,
  - only applies to terminal illness
  - not to persistent vegetative (PVS) or minimally conscious states
- Few doctors would certify PVS and comatosed patients as terminally ill as they can be sustained for years with good care
- If terminal illness is present, most doctors would not offer life sustaining treatment on the grounds of medical futility

# How useful is the AMD in Singapore?

- Advanced malignancies
  - 75 yr man with metastatic adenocarcinoma, unknown primary, with mets to brain, lungs, liver. He has features of a chest infection and is breathless and hypotensive….
  - Would you consider?
    - Intubation and artificial ventilation
    - IV antibiotics
    - NG tube feeding if he is unable to take orally?

# Clinical scenarios

- Recurrent Stroke
  - 75 yr man with recurrent strokes, bedbound, contractures, dysphasic, on tube feeding, pressure sores, recurrent aspiration pneumonias.
  - Would you consider?
    - Intubation and artificial ventilation
    - IV antibiotics
    - IV blood transfusion if he is anemic?

# Clinical scenarios

…. **a moot point**

- Extraordinary Life Sustaining measures will not be pursued anyway in the first situation mentioned.
- May be an issue only if there are disagreements between physician's assessment of futility and family's.
- In these patients, it is also quite unlikely that patient has drawn up an AMD.

# When "terminal" is …

# When “terminal” is …

**… relative**

- Consideration shifts from medical futility to **quality of life** in many patients with advance illnesses
  - Who determines what is poor quality of life
    - Patient ?
    - Care giver and family ?
    - Health care professional ?
    - Society ?

- Too restrictive
- Cannot appoint substitute decision-maker
- Highly confidential –
  - Since no one knows and cannot ask, seldom activated
- Cumbersome activation process
- Does not address the communication and thought processes behind the decision

- Hospitals have their own policies/protocols/terminology
  - Do Not Resuscitate
  - Maximal ward management
  - Best Supportive Care
  - Conservative Management
- Documents developed to deal with the problem
- Documents only good for a particular admission
- Information unavailable to other health services and on transfer to community settings

# Clinical decisions

# **Advanced Directives:**

Coming up with a new framework

| | |
|---|---|
| Legal Process | Communication Process |
| Highly Confidential | Open Disclosure |
| Stand-alone | Incorporation into care systems |
| Cumbersome Activation | Guide to Decision Making |

Living Matters
advance care planning

- A nation-wide initiative
- Collaboration with Respecting Choices®
  - Education and System framework
- Initial initiatives and engagement in 2009

- Systems to honor preferences
  - Develop common documentation
  - Information accessibility across healthcare sectors

- ACP Facilitation, Education and Training
  - Training of ACP Facilitators
    - Aim is not to complete a form
    - Instead, it is a communication process – integrated into routine patient care
    - Staged based on a person's state of health
  - Maintain competency of trained facilitators

# 4 Key Elements of the ACP programme

- Community Engagement
  - Identify nodal points of contact
  - Referral mechanism with follow-up facilitation

- Continuous Quality Improvement
  - ACP pilots
  - Develop structural framework and systems for ACP
  - Integration of ACP framework into the local healthcare system

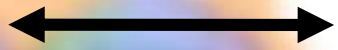
# 4 Key Elements of the ACP programme

# 5 Yr Plan - Integration
# Through Regional Health Services

## RHS Satellite ACP Office

**Each Satellite ACP Office will have:**

- 0.2 FTE clinician lead
- 1 RA/ Executive
- 5 Trainers/ Facilitators
- 1 AA
- 1 Manager

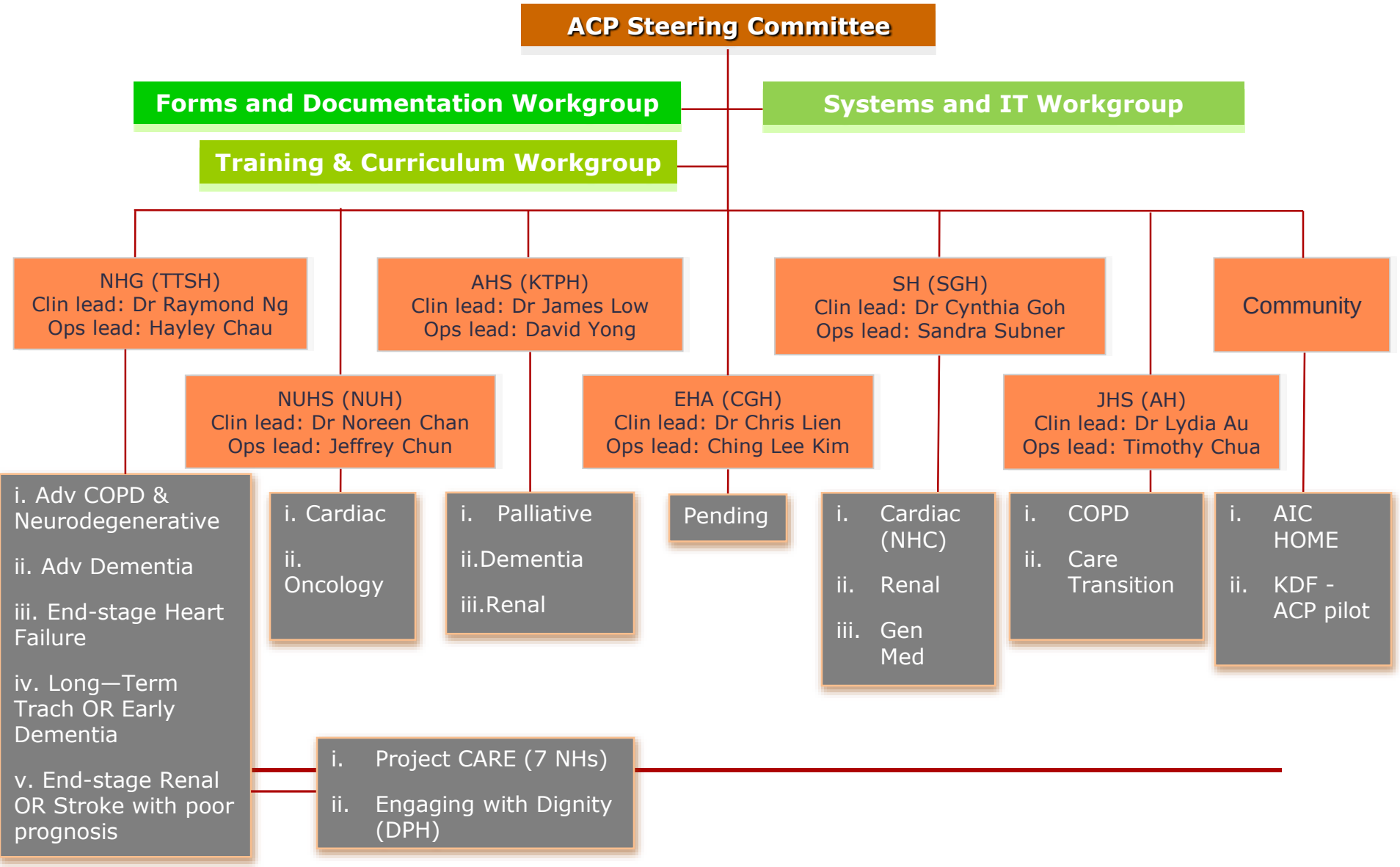


## National ACP Office

Functions:

- 0.5 FTE Executive Director as overall Champion Lead
- 1 FTE Manager Support
- 1 FTE Executive Support
- National integration of ACP, including IT platform
- Centralized ACP facilitator training & certification
- Community Engagement
- Support ACP facilitation for community providers
- Maintain international linkages

# ACP Org Chart & Pilots



# 5 Year Plan– Thrusts & Objectives

**Thrust 1: Increase awareness of ACP**

**Thrust 2: Recruit & train more ACP facilitators**

**Thrust 3: Build & strengthen systems to support ACP implementations**

**Obj: Outreach to Healthcare professionals**

- Awareness Talks (Hops)
- Incorporate **'ACP awareness'** into healthcare curriculum
- Engage RHS on ACP framework

**Obj: Community & Public Engagement**

- Outreach to community leaders
- Outreach to general public

Development of training materials

Conduct ACP facilitator certification courses

Infrastructure set up

IT Development

Documentation and tracking of patient's ACP

**Obj: Develop strategies for ACP training and education**

**Obj: Develop systems to honor preferences**

**Obj: Continuous Quality Improvement**

# 5 Year Plan– Thrusts & Objectives

**Thrust 1: Increase awareness of ACP**

**Obj: Outreach to Healthcare professionals**

- Awareness Talks (Hops)
- Incorporate **'ACP awareness'** into healthcare curriculum
- Engage RHS on ACP framework

**Obj: Community & Public Engagement**

- Outreach to community leaders
- Outreach to general public

**Thrust 2: Recruit & train more ACP facilitators**

Development of training materials

Conduct ACP facilitator certification courses

**Thrust 3: Build & strengthen systems to support ACP implementations**

Infrastructure set up

IT Development

Documentation and tracking of patient's ACP

**Obj: Develop strategies for ACP training and education**

**Obj: Develop systems to honor preferences**

**Obj: Continuous Quality Improvement**

# Local Programme Identity & Collaterals

Living Matters
advance care planning

First Edition

- A set of brochure (in 4 languages), workbook, worksheet and wallet card completed in 2010

Next

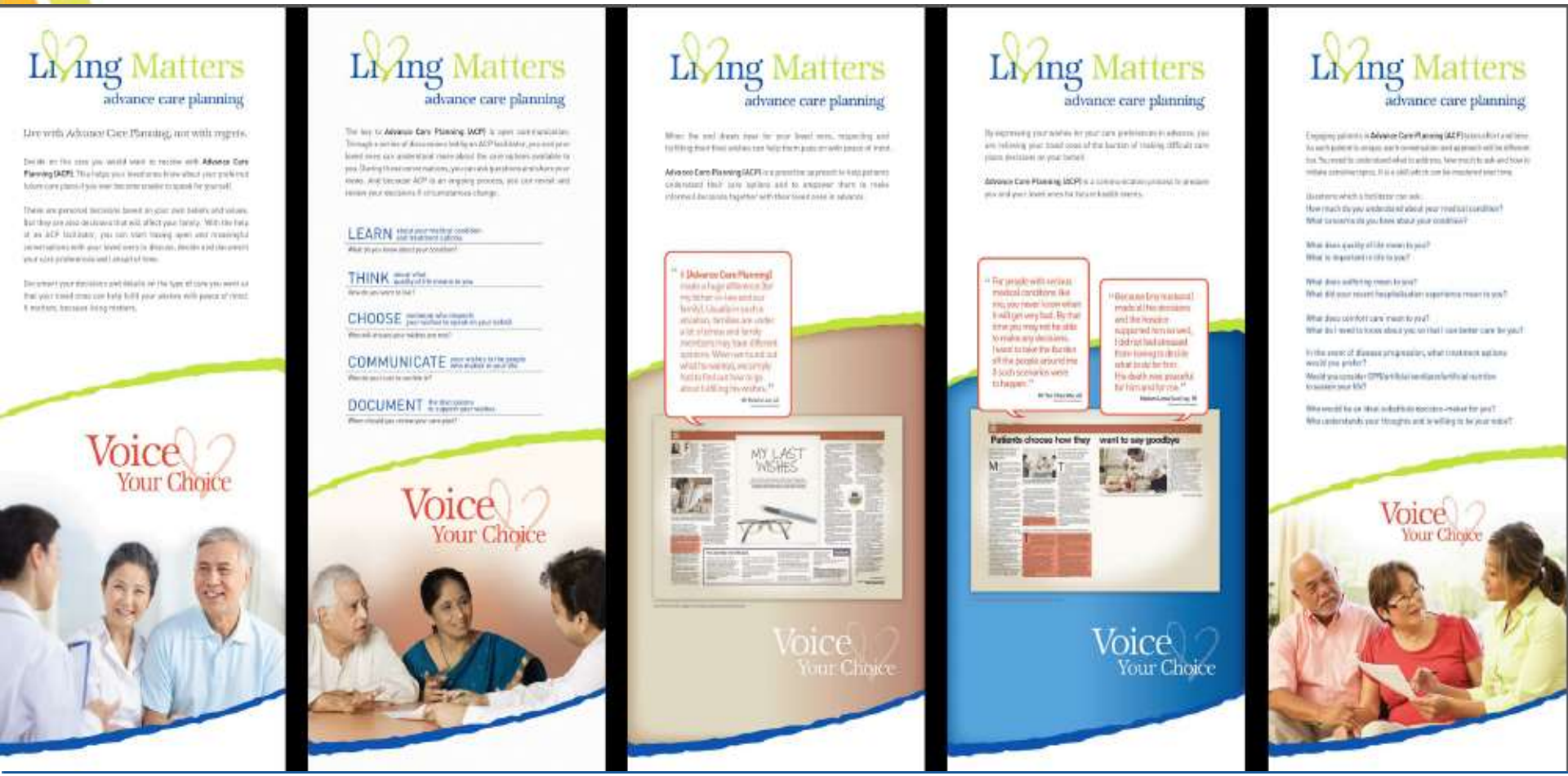
- Revamping the first edition collaterals, eventual aim to have an ACP info-kit
- A set of standing banners for roadshows
- A set of videos for patients and healthcare professionals
- E-modules with embedded role play videos in various languages for self-learning

# Community Engagement – Hospice

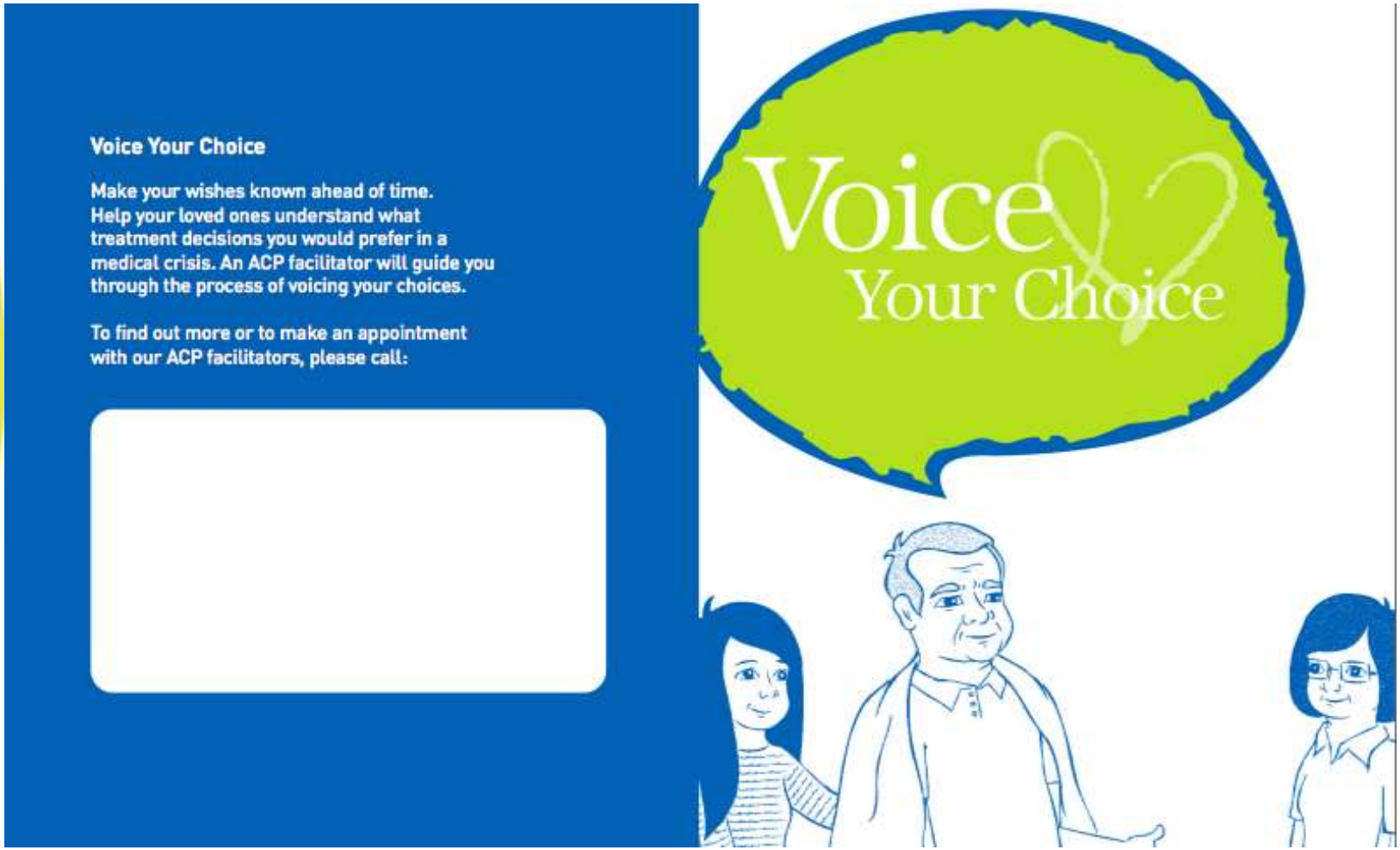
DOVER PARK HOSPICE
Every Moment Matters


# Engagement Materials – Standees/ Banner

Standees to speak to both healthcare professionals and patients



# Printed Collaterals



# Outcomes

- Generally very positive and supportive of ACP
- Recognise the need for ACP
- Public communication needs to be ground-up, not top-down to avoid being perceived as a political agenda
- Supportive of use of IT – **advocate video recording** to avoid conflicts amongst family members
- Recommended incorporating ACP with **retirement planning**
- Engagement of community '**health ambassadors**' to promote ACP

# ACP Community Advocates

**Module 1**
ACP theory

**Module 2**
Communication & listening skills

**Module 3**
Putting it all together as an ACP Advocate

# 5 Year Plan– Thrusts & Objectives

**Thrust 1:**
**Increase awareness of ACP**

**Thrust 2:**
**Recruit & train more ACP facilitators**

**Thrust 3:**
**Build & strengthen systems to support ACP implementations**

**Obj: Outreach to Healthcare professionals**

- Awareness Talks (Hops)
- Incorporate **'ACP awareness'** into healthcare curriculum
- Engage RHS on ACP framework

Development of training materials

Conduct ACP facilitator certification courses

Infrastructure set up

IT Development

Documentation and tracking of patient's ACP

**Obj: Community & Public Engagement**

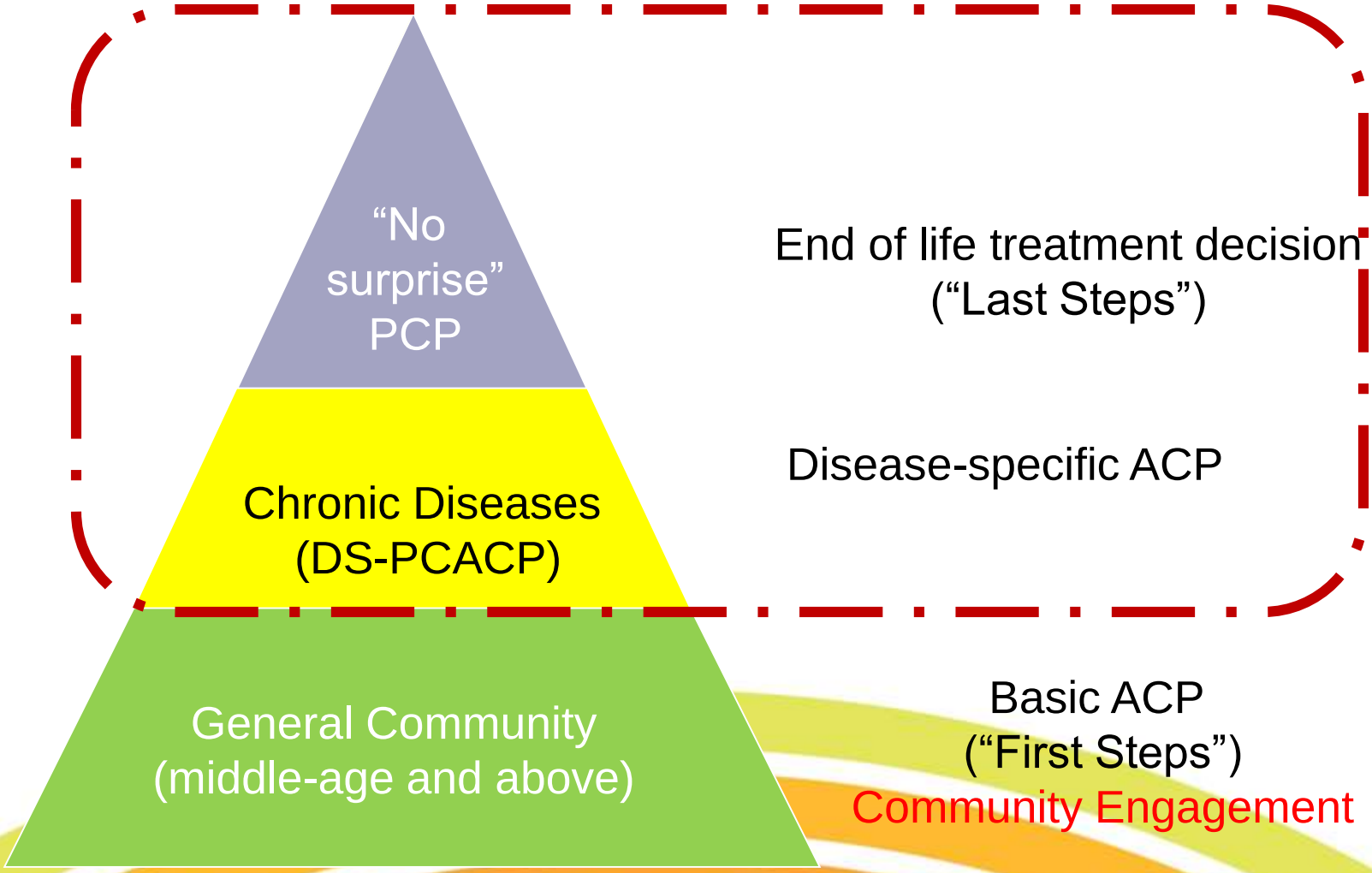
- Outreach to community leaders
- Outreach to general public

**Obj: Develop strategies for ACP training and education**

**Obj: Develop systems to honor preferences**

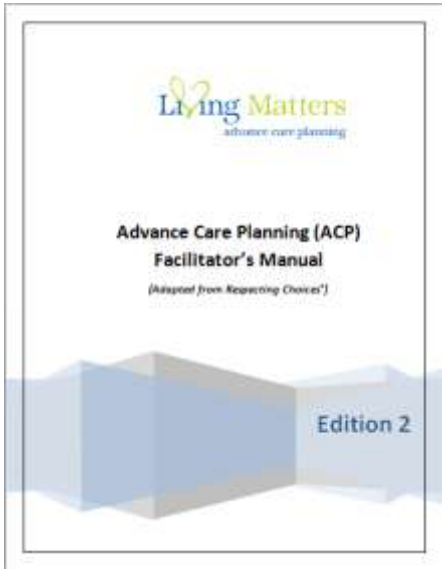
**Obj: Continuous Quality Improvement**

# ACP Paradigm



# Recruit and train more facilitators

- Emphasis :
  - Patient's understanding
  - Patient's experience
  - Patient's values
  - What would be important for the patient to "live well"




**To date, more than 600 facilitators have been trained**

# 5 Year Plan– Thrusts & Objectives

**Thrust 1:**
**Increase awareness of ACP**

**Thrust 2:**
**Recruit & train more ACP facilitators**

**Thrust 3:**
**Build & strengthen systems to support ACP implementations**

**Obj: Outreach to Healthcare professionals**

- Awareness Talks (Hops)
- Incorporate **'ACP awareness'** into healthcare curriculum
- Engage RHS on ACP framework

**Obj: Community & Public Engagement**

- Outreach to community leaders
- Outreach to general public

Development of training materials

Conduct ACP facilitator certification courses

**Obj: Develop strategies for ACP training and education**

Infrastructure set up

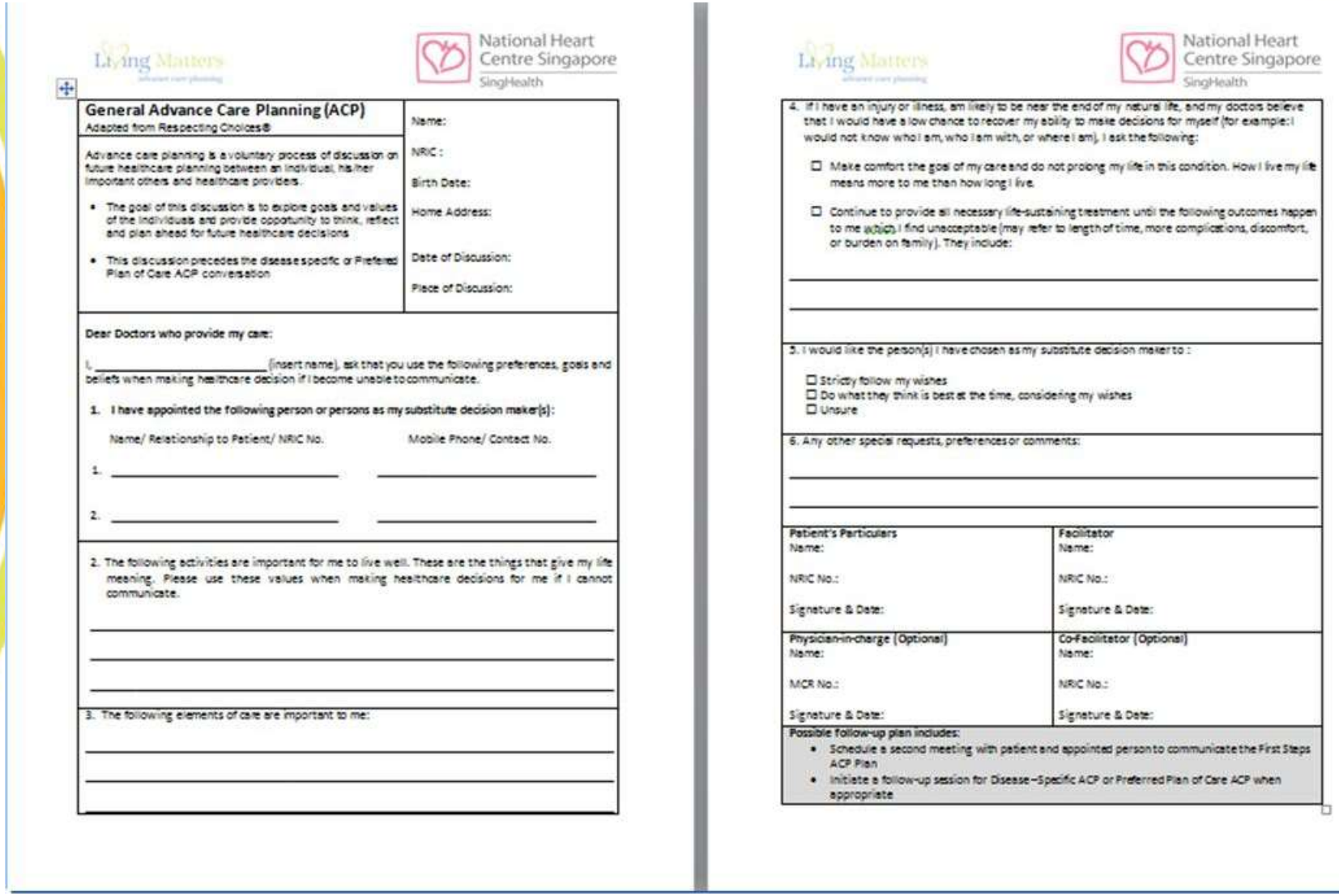
IT Development

Documentation and tracking of patient's ACP

**Obj: Develop systems to honor preferences**

**Obj: Continuous Quality Improvement**

# ACP Documentation – General ACP



Living Matters

National Heart Centre Singapore
SingHealth

**General Advance Care Planning (ACP)**
Adapted from Respecting Choices®

Advance care planning is a voluntary process of discussion on future healthcare planning between an individual, his/her important others and healthcare providers.

- The goal of this discussion is to explore goals and values of the individuals and provide opportunity to think, reflect and plan ahead for future healthcare decisions
- This discussion precedes the disease specific or Preferred Plan of Care ACP conversation

Name:

NRIC :

Birth Date:

Home Address:

Date of Discussion:

Place of Discussion:

**Dear Doctors who provide my care:**

I, _____ (insert name), ask that you use the following preferences, goals and beliefs when making healthcare decision if I become unable to communicate.

1. **I have appointed the following person or persons as my substitute decision maker(s):**

| Name/ Relationship to Patient/ NRIC No. | Mobile Phone/ Contact No. |
|---|---|
| 1. _____ | _____ |
| 2. _____ | _____ |

2. The following activities are important for me to live well. These are the things that give my life meaning. Please use these values when making healthcare decisions for me if I cannot communicate.

_____

_____

_____

3. The following elements of care are important to me:

_____

_____

_____

Living Matters

National Heart Centre Singapore
SingHealth

4. If I have an injury or illness, am likely to be near the end of my natural life, and my doctors believe that I would have a low chance to recover my ability to make decisions for myself (for example: I would not know who I am, who I am with, or where I am), I ask the following:

☐ Make comfort the goal of my care and do not prolong my life in this condition. How I live my life means more to me than how long I live.

☐ Continue to provide all necessary life-sustaining treatment until the following outcomes happen to me which I find unacceptable (may refer to length of time, more complications, discomfort, or burden on family). They include:

_____

_____

5. I would like the person(s) I have chosen as my substitute decision maker to :

☐ Strictly follow my wishes
☐ Do what they think is best at the time, considering my wishes
☐ Unsure

6. Any other special requests, preferences or comments:

_____

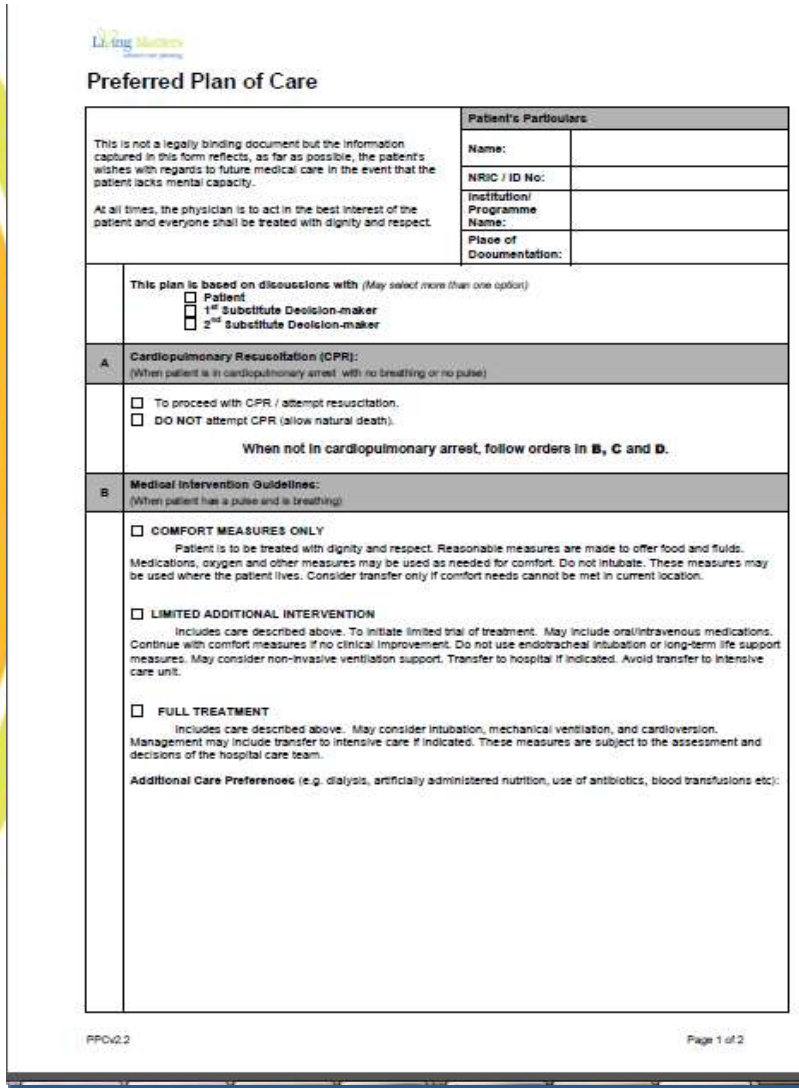
_____

| Patient's Particulars | Facilitator |
|---|---|
| Name: | Name: |
| NRIC No.: | NRIC No.: |
| Signature & Date: | Signature & Date: |
| **Physician-in-charge (Optional)** | **Co-Facilitator (Optional)** |
| Name: | Name: |
| MCR No.: | NRIC No.: |
| Signature & Date: | Signature & Date: |

**Possible follow-up plan includes:**

- Schedule a second meeting with patient and appointed person to communicate the First Steps ACP Plan
- Initiate a follow-up session for Disease-Specific ACP or Preferred Plan of Care ACP when appropriate

# ACP Documentation – Preferred Plan of Care



Living Matters

## Preferred Plan of Care

This is not a legally binding document but the information captured in this form reflects, as far as possible, the patient's wishes with regards to future medical care in the event that the patient lacks mental capacity.

At all times, the physician is to act in the best interest of the patient and everyone shall be treated with dignity and respect.

| Patient's Particulars | |
|---|---|
| Name: | |
| NRIC / ID No: | |
| Institution/ Programme Name: | |
| Place of Documentation: | |

**This plan is based on discussions with** *(May select more than one option)*
- ☐ Patient
- ☐ 1st Substitute Decision-maker
- ☐ 2nd Substitute Decision-maker

**A — Cardiopulmonary Resuscitation (CPR):**
(When patient is in cardiopulmonary arrest with no breathing or no pulse)

- ☐ To proceed with CPR / attempt resuscitation.
- ☐ DO NOT attempt CPR (allow natural death).

**When not in cardiopulmonary arrest, follow orders in B, C and D.**

**B — Medical Intervention Guidelines:**
(When patient has a pulse and is breathing)

☐ **COMFORT MEASURES ONLY**
Patient is to be treated with dignity and respect. Reasonable measures are made to offer food and fluids. Medications, oxygen and other measures may be used as needed for comfort. Do not intubate. These measures may be used where the patient lives. Consider transfer only if comfort needs cannot be met in current location.

☐ **LIMITED ADDITIONAL INTERVENTION**
Includes care described above. To initiate limited trial of treatment. May include oral/intravenous medications. Continue with comfort measures if no clinical improvement. Do not use endotracheal intubation or long-term life support measures. May consider non-invasive ventilation support. Transfer to hospital if indicated. Avoid transfer to intensive care unit.

☐ **FULL TREATMENT**
Includes care described above. May consider intubation, mechanical ventilation, and cardioversion. Management may include transfer to intensive care if indicated. These measures are subject to the assessment and decisions of the hospital care team.

**Additional Care Preferences** (e.g. dialysis, artificially administered nutrition, use of antibiotics, blood transfusions etc):

PPCv2.2 Page 1 of 2

Living Matters

**C — Preferred place of medical treatment and care in event of deterioration**

- ☐ Remain in my own home / nursing home / hospice /hospital
- ☐ Trial of treatment in own home / nursing home / hospice before considering transfer to hospital
- ☐ Transfer to hospital
- ☐ Others (transfer to hospice, etc) _____

**D — Preferred Place of Death in event of deterioration**

- ☐ Nursing Home
- ☐ Own Home
- ☐ Acute Hospital
- ☐ Inpatient Hospice

**D — Other important notes**

| Patient's Particulars: | 1st Substitute Decision-maker: | 2nd Substitute Decision-maker: |
|---|---|---|
| Name: | Name: | Name: |
| NRIC No: | NRIC No: | NRIC No: |
| | Relationship: | Relationship: |
| | Contact No: | Contact No: |
| Signature: | | |
| Date: | Signature & Date: | Signature & Date: |

| Facilitator: | Physician-in-charge |
|---|---|
| Name: | Name: |
| Last 4 NRIC No. | MCR No: |
| Signature & Date: | Signature & Date: |

**Directions For Healthcare Professionals**

When completing the "Preferred Plan of Care" document:
- Any incomplete section of the Preferred Plan of Care form will require physician's discretion, as indicated.
- Tick ☑ all relevant boxes in the form.
- This document must be completed by healthcare professional based on the patient preferences and medical indications.
- The Preferred Plan of Care must be signed by a physician to be valid.
- Photocopies and faxes of signed Preferred Plan of Care are valid.
- Place this document at the front of the patient's case notes during each hospitalization.
- This document serves to guide and not dictate medical treatment.
- The patient may verbally change his/her preferences.
- Contact the facilitator or physician-in-charge for any queries.

**Review Of These Preferred Plan of Care**

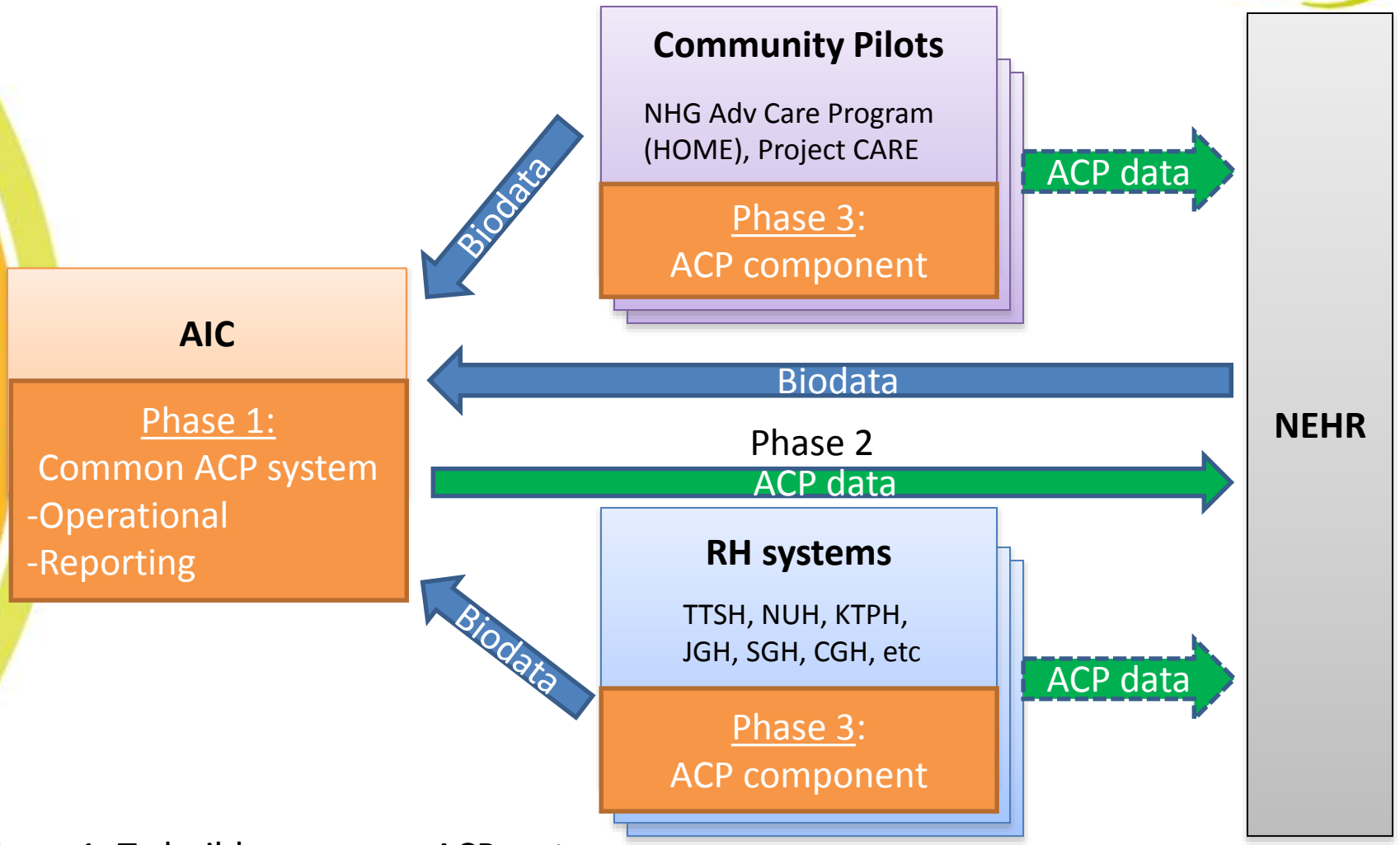
Preferred Plan of Care should be reviewed if:
- The patient is transferred from one care setting or care level to another, or
- There is substantial change in the patient's health status, or
- The patient's treatment preferences change.

If this form is to be voided, write "VOID" in large letters and draw a line across both sides of the form. After voiding the form, complete a new form if required.

**THIS FORM IS TO ACCOMPANY THE PATIENT UPON TRANSFER OR DISCHARGE**

PPCv2.2 Page 2 of 2

# Systems Data Flow (high level concept)




Phase 1: To build a common ACP system

Phase 2: To feed ACP data to NEHR (when ready)

Phase 3 : Development/integration with ACP components at the institutions/community

# ACP Documentation

Emphasis is not on form filling. In fact, need not be a form.

- Letter
- “Certificate”
- Oral communication

- Communication of Preferences
- Understanding of Values

# Challenges

1. Harmonization
   - Consensus between users on documentation format, data fields etc. in ACP IT system
2. Follow-up
   - How to ensure follow-up in the community post-discharge from hospital
   - Tracking of final outcome
3. Buy-in
   - Primary care physicians and other healthcare professionals
   - Community sector including religious and grassroots leaders
   - Messages to public are well received with appropriate feedback channels

# Challenges

4. ACP must be supported by palliative care programmes
   - National Strategy for Palliative Care
   - Palliative care programmes in each cluster, stretching across hospitals to community
   - Encompassing specialist palliative care and palliative care approaches in hospital, community and primary care settings

5. Improving bereavement programmes nationwide

   ? The next piece in the puzzle


**"Some time back, I had an Advanced Medical Directive (AMD) done which says that if I have to be fed by a tube, and it is unlikely that I would ever be able to recover and walk about, my doctors are to remove the tube and allow me to make a quick exit."**

**Lee Kuan Yew**
**"One Man's View of the World"**

Thank You