

# Advance Care Planning: What do we know about the economic case?

Josie Dixon, Tihana Matosevic, Derek King, Martin Knapp

# Advance care planning

- Advance statements
- Advance decision to refuse treatment (advance directives)
- Lasting power of attorney (durable power of attorney/ DPOA)
- Mental Capacity Act, 2005

# MyDirectives

## Q What is important to you?

If you're seriously ill and can't make your wishes known, you would obviously want your doctors to try to improve your condition. But, in case they can't, you might want them to know the things about your life and health that you value most. ([Read what some seriously ill people have answered.](#))

(Check all that apply, and then prioritize them in the list to the right.)

- Being free from pain
- Being with my family
- Being able to feed, bathe, and take care of myself
- Not being a financial burden to my family
- Not being a physical burden to my family
- Being at peace with my God
- Resolving conflicts
- Avoiding prolonged dependence on machines
- Avoiding prolonged dependence on artificial or assisted nutrition through tubes
- Dying at home
- Other things that are very important to me about life and health...

Type here...

### My Priorities

- |   |   |   |   |
|---|---|---|---|
| 1 | Being free from pain  | × | ↕ |
| 2 | Being with my family  | × | ↕ |
| 3 | Avoiding prolonged dependence on machines                                       | × | ↕ |
| 4 | Avoiding prolonged dependence on artificial or assisted nutrition through tubes | × | ↕ |
| 5 | Other things that are very important to me about life and health...             | × | ↕ |

# MyDirectives

**Q** If it were possible to choose, where would you like to spend your final days?

- At home...
  - I want [hospice](#) care at home if possible.
- In the hospital...
- In a [hospice](#) facility
- I'm not sure

[I have additional thoughts on this...](#)

---

Q If you have a severe, irreversible [brain injury](#) or illness and can't dress, feed, or bathe yourself, or communicate your medical wishes, but doctors can keep you alive in this condition for a long period of time, which of the following statements best describes what you'd like to tell them?

- I prefer that they stop all [life-sustaining treatments](#) and let me die as gently as possible. I realize that I would not receive life-sustaining treatments including but not limited to [breathing machines](#), [blood transfusions](#), [dialysis](#), [heart machines](#), and [IV drugs](#) to keep my heart working. Also, I realize that [cardiopulmonary resuscitation \(CPR\)](#) would not be attempted, and I would be allowed to die naturally.
- I would like them to keep trying [life-sustaining treatments](#)...
- Neither of the choices above reflects my preference, and I have additional thoughts on this...

Now let's consider your thoughts related to attempted [cardiopulmonary resuscitation \(CPR\)](#). Doctors generally consider attempting CPR appropriate when death occurs unexpectedly (in other words, when an otherwise healthy person dies suddenly). However, CPR is not considered appropriate when death is expected, such as for a patient that is [terminally ill](#) or that has a severe, irreversible [brain injury](#). [More...](#)

# Respecting Choices

- If you reach a point where treatments will extend your life by a few months and side effects are pretty serious, would you want doctors to stop, or continue to do all that could be done?

# Context

- Shift in profile of dying – older, non-cancer
- US – Patient Self-Determination Act, 1990
- National End of Life Care Strategy 2008
- National End of Life Care Programme (NEoLP)
- National End of Life Care Intelligence Network (NEoLCIN)

# Social care role

- Supporting People to Live and Die Well
- ‘Routes to Success’ guidance
- Training and development
- Care assessment, support planning and personalization processes
- Holistic care – socio-legal, relationships, finances



# Benefits

- Less hospitalisation in last year/ 3 months
- Fewer marginal, aggressive medical interventions
- Earlier accessing of hospice/ palliative care
- Better quality of life at end of life
- Reduced stress and burden for caregivers
- Fewer hospital deaths
- Reduced depression/ anxiety in bereaved caregivers
- Greater satisfaction with end of life care

# Study aims

- Map what is known about the economic case for ACP
- Explore literature for evidence on costs, risks and outcomes
- Model the economic (and other) consequences of ACP for a cohort of older decedents
- Clarify the limitations of available evidence for economic evaluation

What does the literature say  
about cost effectiveness?

# Findings mixed

- Two early RCTs in US = no reduction in costs (Schneiderman et al., 1992; Teno et al., 1997)

However cost benefits found in ...

- ‘Let Me Decide’ in care homes (Molloy et al., 2000)
- High and medium spending areas in US (Nicholas et al., 2011)

# Scope for savings

- 104 million on 1.8 billion by reducing emergency admissions and length of stay (NAO/ RAND, 2008)
- £300 million through achievable 25% reduction in hospital deaths (Balance of Care Group, 2008)
- 10% unnecessary admissions, case note review of 100 decedents (Ahearn et al., 2013)
- 93 care home residents dying in UK hospital over 6 months, 40% died within 24 hrs of admission (Ong et al., 2011)

# Baker et al., 2012

- Advance planning initiative with case managed, intensive community support
- Cost of additional staffing = £125,000
- Savings from reduced unplanned hospitalization = £144,000
- No other costs considered
- Small, single site N=96 participants (matched), 15 decedents

# Abel et al., 2012

- Decedents known to hospice in 2.5 year period
- N= 969 (550, with ACP)
- Hospital deaths: ACP = 11%, no ACP = 26%
- Hospital costs last year: ACP = £8657, no ACP = £14,310
- Hospital deaths national average = 51%
- Single site, in care of hospice, mostly cancer patients, only hospital costs considered

# Modelling

- Modelling useful where empirical evidence is limited, unclear or complex
- Can explore and change assumptions
- Simple decision model for cohort of people age 65+ at end of life (and 6-12 months after death for caregivers)



# What proportion have an ACP?

# US estimates

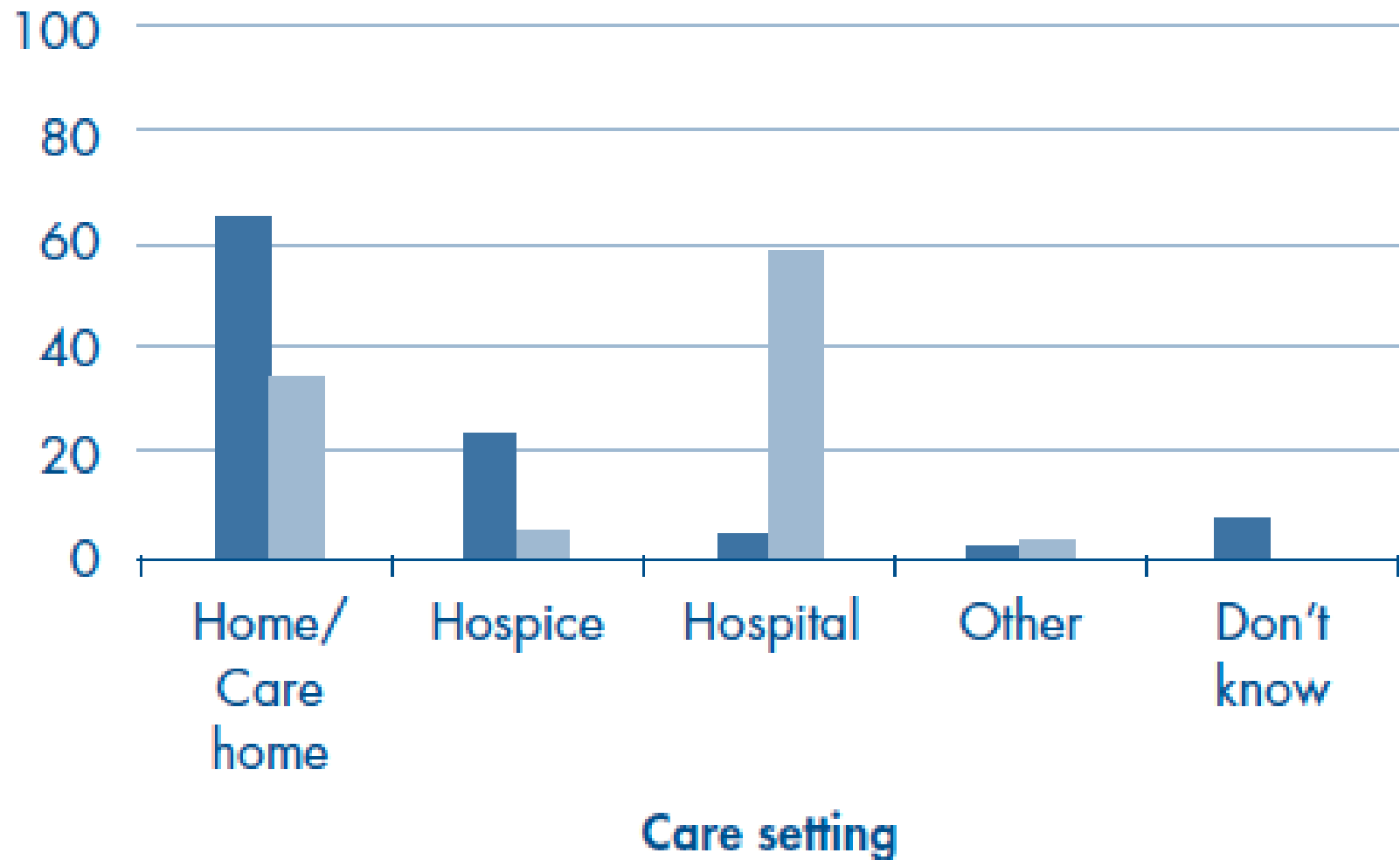
- < 33% - general population, various surveys, reported by Stein and Fineberg, 2013
- 90% - Respecting Choices (Hammes et al., 2010)
- 76% - Bischoff et al. 2013, HRS n=4399 decedents, mean age 82.6

# UK estimates

- 12% age 75+ with advance decision, 5% all ages (BSA, 2013)
- 52% decedents known to UK hospice with a recorded place of death in records (Abel et al., 2013)
- 15%-62% increase in recorded advance care planning discussions for people on end of life register, evaluation of 'Going for Gold' accredited GP surgeries

# ACP and place of death

Percentage



■ Care preference

■ Actual place of death

# Barriers

- Not practical (e.g. no primary caregiver)
- Late recognition
- Clinical need (challenges of prognosis, complex symptom management, comorbidities)
- Physicians may be unaware of ACP/ lack training
- Family may have opposing preferences
- Validity and applicability of ACP (e.g. may be too vague or specific for circumstances)

# Hospital death

- 37% with treatment limiting advance directive vs 47% with no ACP (Nicholas et al., 2011)
- 39% with any ACP vs 49% with no ACP (Bischoff et al., 2013)
- 38% (of those needing decision making and lacking capacity) with advance directive and/or DPOA vs 53% with neither (Silveira et al., 2010)

# Associated costs



Comparing the weekly costs of community palliative care with specialist in-patient palliative care.

	Cost per contact	Contacts per week	Cost per week	Cost per day
District nursing *	£39	2.3	£91	£13
Community nursing (8 hours per contact) ^	£246	1.9	£465	£66
Social care ~			£191	£27
Community Nurse Specialist (1 hour)	£77	1	£77	£11
Outpatient attendance	£194	1	£194	£28
<b>Total community</b>			<b>£1,019</b>	<b>£145</b>
<b>Hospital in-patient specialist palliative care *</b>			<b>£2,975</b>	<b>£425</b>

Figures are shown to the nearest £, but calculations based on unrounded figures.

\* = Unit Costs of Health and Social Care, University of Kent, 2010

^ = Marie Curie Nursing Service data

~ = Social Care and Hospital Use at the End of Life, Nuffield Trust, 2010

# NEoLCP Cohort Model

Average cost health and social care last days in community  
(weighted by deaths in each trajectory for 2009) = £1123

	<b>Possible per patient community staff costs</b>			
	Early recognition	Ongoing support	Last days	Total
Cancer	£338	£2,724	£855	£3,917
Other terminal illness	£1,276	£13,970	£1,156	£16,402
Frailty	£454	£12,792	£1,011	£14,257
Organ failure	£997	£10,311	£1,226	£12,534
Sudden death	N/A	N/A	£1,324	£1,324

# Episode ending in death in community

- Hospice at Home (West Kent) - £1200
- Royal Marsden H2H – approx £1365
- The DALE service (to enable facilitated discharge to die at home) - £2,800
- NEoLCIN, What We Know Now, 2012 - £2,506 (£1415 - £2800)

# Marie Curie 'Delivering Choice'

**TABLE 10: SUMMARY OF AVERAGE ACUTE AND COMMUNITY COSTS PER PATIENT WITH CANCER IN THE LAST EIGHT WEEKS OF LIFE IN BOSTON (page 29)**

	Average cost per person in acute sector (standard deviation)	Average cost per person in community sector (standard deviation)	Total average cost per person (standard deviation)
Sample of 40 patients before the introduction of the programme	£2,636 (£2,495)	£2,689 (£1,911)	£5,324 (£2,910)
Sample of 40 patients who accessed programme services	£2,509 (£3,405)	£2,892 (£3,706)	£5,401 (£4,409)

Includes day care, night care, ambulance discharge, district nurses, registered, after hours paramedic, hospice services, health care assistant, social service assessment, home care, equipment.

# Facilitation of ACP costs

- Model very sensitive to these costs
- Build into existing processes (e.g. dementia diagnosis)
- Special initiatives – *‘complex interventions were found to result in an increased frequency of out of hospital and out of ICU care’* (Brinkman-Stoppelenburg et al., 2014)

# Caregiver costs

- Costs for family caregivers omitted from cost evaluations (SCIE, 2013; Dumont et al., 2010)
- ‘Bedside’ care even if in hospital or residential care
- Caregivers at end of life are especially negatively impacted (Williams et al., 2013)
- But potential benefits in reduced anxiety/ depression and increased satisfaction (Detering et al., 2010)

Thank you!

For further information email Josie Dixon:  
[j.e.dixon@lse.ac.uk](mailto:j.e.dixon@lse.ac.uk)

This presentation reports on independent research funded by the NIHR School for Social Care Research. The views expressed in this presentation are those of the authors and not necessarily those of the NIHR School for Social Care Research or the Department of Health/NIHR.