Advance Care Planning in Canada

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THETA Symposium on End-of-Life Care

Toronto, ON

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CARENET
Canadian Researchers at the End of Life Network

McMaster University
HEALTH SCIENCES

Objectives

1. To discuss national initiatives aimed at improving Advance Care Planning (ACP)
2. To share early results from 2 ongoing, inter-related, multi-centre studies of EOL communication at Canadian acute care hospitals

A patient I recently cared for

88 Polish widow, home alone, 3 children nearby

Depression

Diabetes on insulin

Myocardial infarction 2006, stents 2006 &2007

Diastolic heart failure (LVEF 55%)

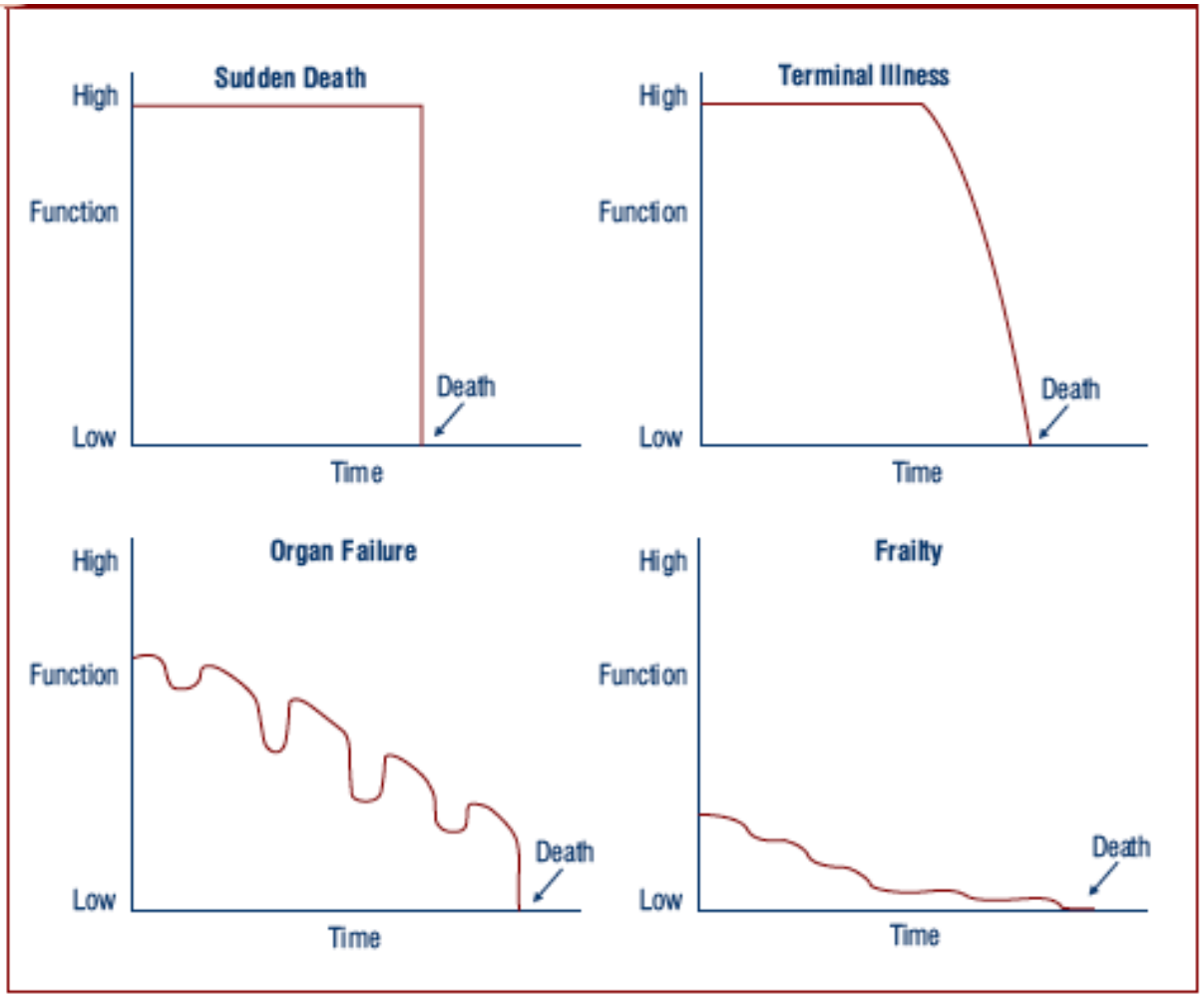
Chronic obstructive lung disease (FEV1 35%)

Osteoporosis, vertebral compression # (L1)

Mrs W's illness trajectory

- Oct 2012: 12 day CTU admission for CHF, concerns about frailty, discharged home (12 meds on admission, 14 meds on discharge)
- Dec-Jan 2013: 25 day CTU admission for CHF, "deconditioned", discharged to "Assess and Restore" program with plan for retirement home (18 meds on discharge)
- Feb 2013: 90 day hospital admission, cardiac arrest, prolonged ICU stay. Died.

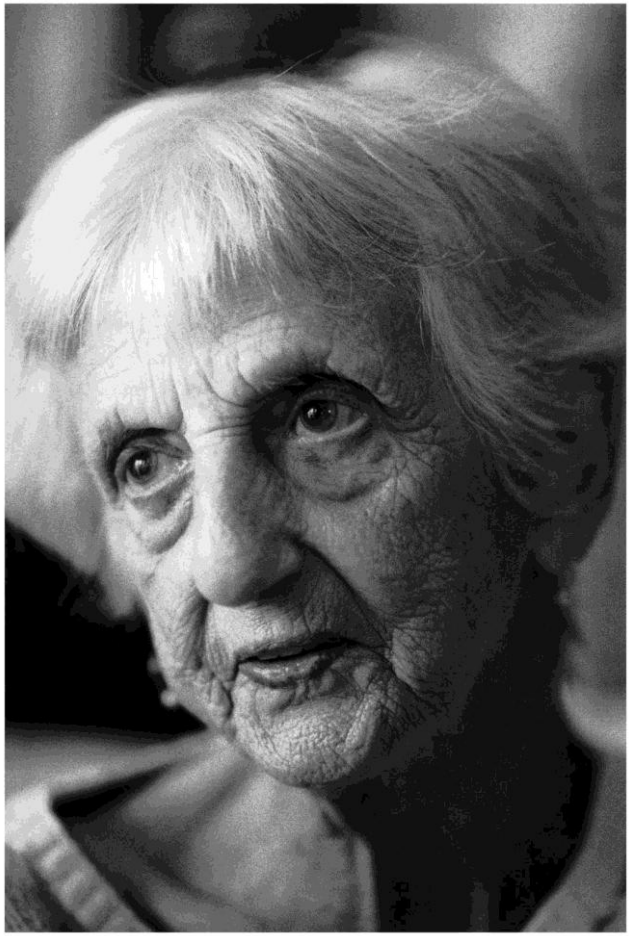
Trajectories of dying



Source: J. Lunney, J. Lynn, C. Hogan, "Profiles of Older Medicare Decedents." *Journal of the American Geriatric Society*, 50 (2002), pp. 1108–1112.

“The Grey tsunami”….

- 2/3 will die with 2 or more chronic diseases after yrs in state of “vulnerable frailty”
- Only 20% will die with a recognizable “palliative” phase
- At time of death:
  - 42.5% of pts required decision making (DM)
  - 70.3% lacked DM capacity



Lynn. “Living Long in Fragile Health”; Bern-Klug. Health Soc Work. 2004; Silveira et al. N Engl J Med; 2010

RESEARCH

What matters most in end-of-life care: perceptions of seriously ill patients and their family members

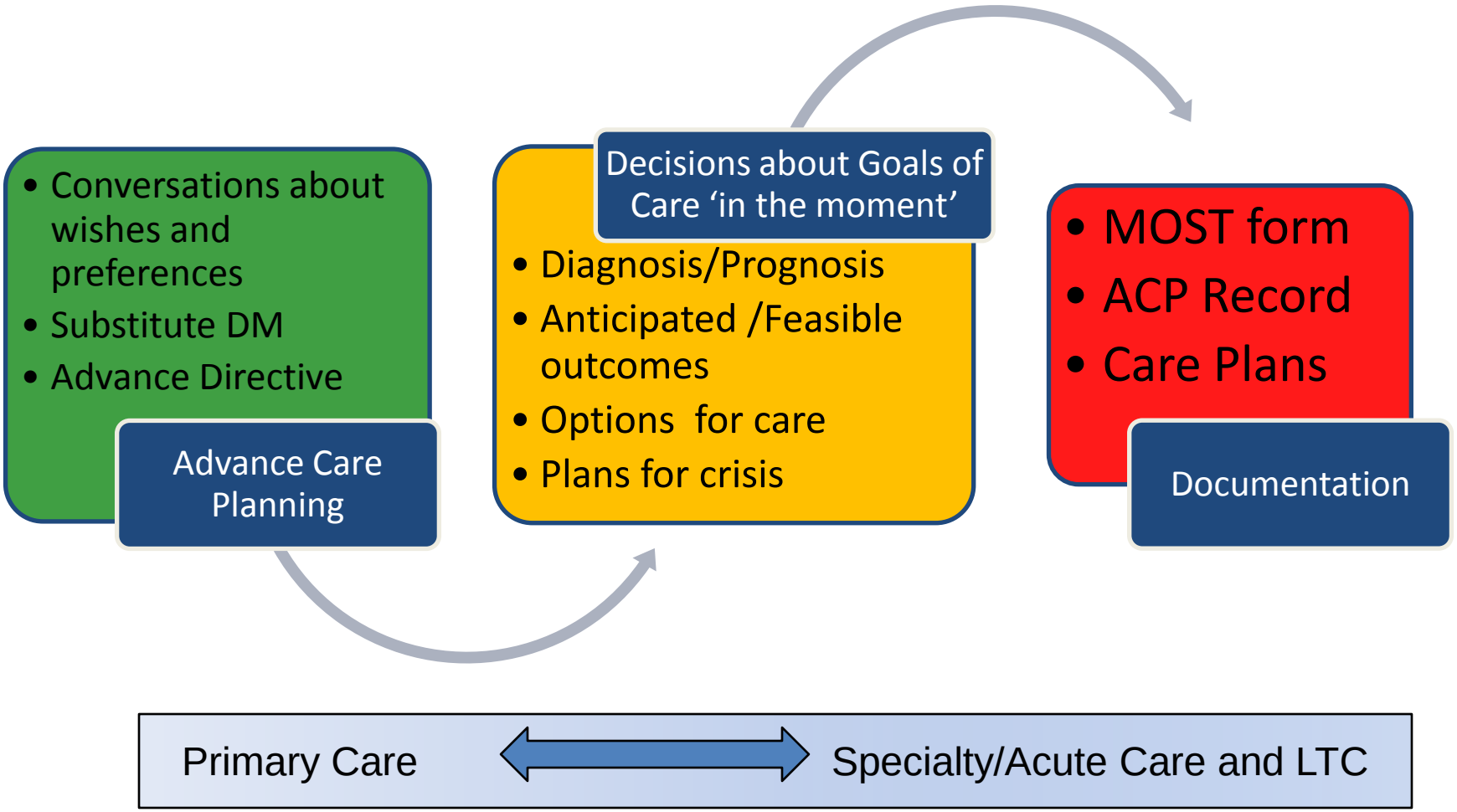
Daren K. Heyland, Peter Dodek, Graeme Rocker, Dianne Groll, Amiram Gafni, Deb Pichora, Sam Shortt, Joan Tranmer, Neil Lazar, Jim Kutsogiannis, Miu Lam, for the Canadian Researchers, End-of-Life Network (CARENET)

How important is it …	% “Extremely Important”
To have trust and confidence in the Doctor looking after you	55.8
To have an adequate plan of care & services available at home upon discharge	41.8
To not be a physical or emotional burden	41.8

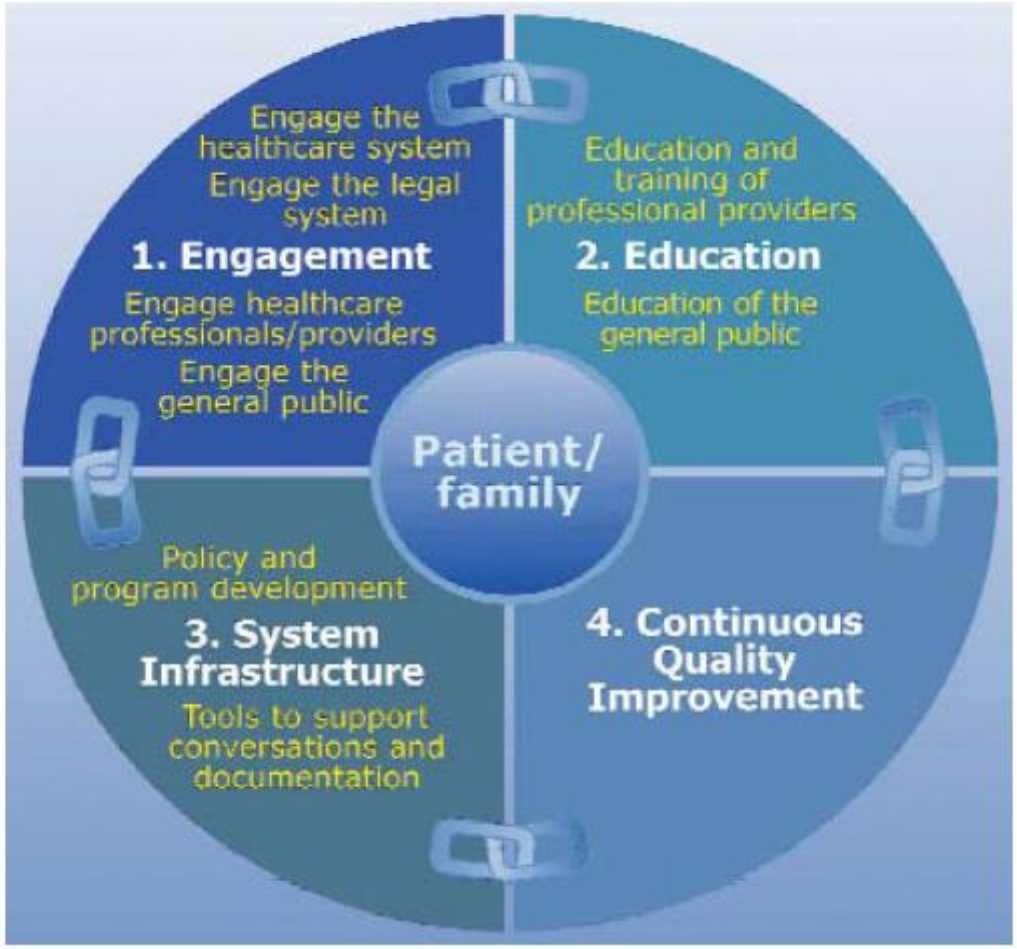
Good end-of-life communication and decision-making

Heyland DK et al. CMAJ. 2006.

EOL communication & decision-making



Framework for Advance Care Planning in Canada



Ipsos Healthcare
The Healthcare Research Specialists

Advance Care Planning – Results of Canadian Sample

fraserhealth
Better health.
Best in health care.

Canadian Hospice Palliative Care Association
Association canadienne de soins palliatifs

CARENET
Canadian Researchers at the End of Life Network

March 2012

Speak Up
Start the conversation about end-of-life care

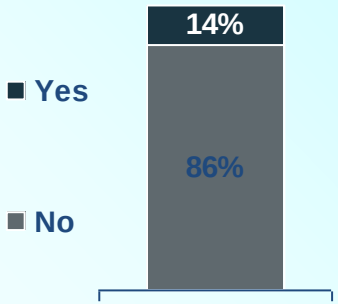
Sample Demographics

		Canada
	Demographic	Base: (n=1021)
Gender	Male	487
	Female	534
Age	18-34	231
	35-54	386
	55+	404
Education	<HS	81
	HS	330
	Post Sec	480
	Univ Grad	130
Household income	<$30K	216
	$30K - <$60K	337
	$60K+	468
Region	BC	189
	AB	129
	SK/MB	77
	Ontario	326
	Quebec	231
	Atlantic	68

Total Respondents: Advance Care Planning

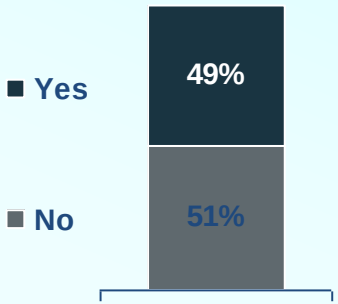
Advance care plans are verbal or written instructions that make your wishes known about the kind of healthcare you want (or do not want) if you become very ill or injured and are unable to speak for yourself. These are sometimes also called 'living wills.'

Heard of 'advance care planning'?

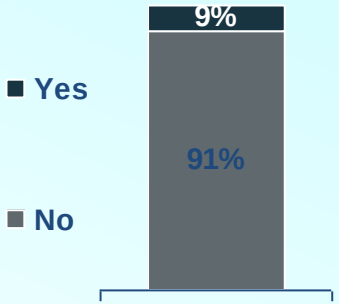


Ever had a discussion regarding healthcare treatment(s) if you became very ill / injured and were unable to speak for yourself?

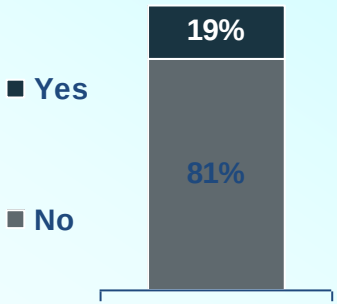
With family / a close friend



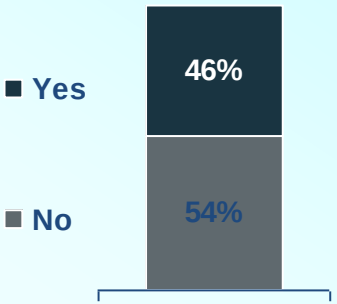
With a healthcare provider



Have an Advance Care Plan written down?



Designated someone to make healthcare decisions for you?



Base: All Respondents (n=1021); Q1 – Q5

ACCEPT Study

Advance Care Planning Evaluation in Hospitalized Elderly Patients: a multicenter, prospective study

Overall PI: Daren Heyland (Queen's Univ.)

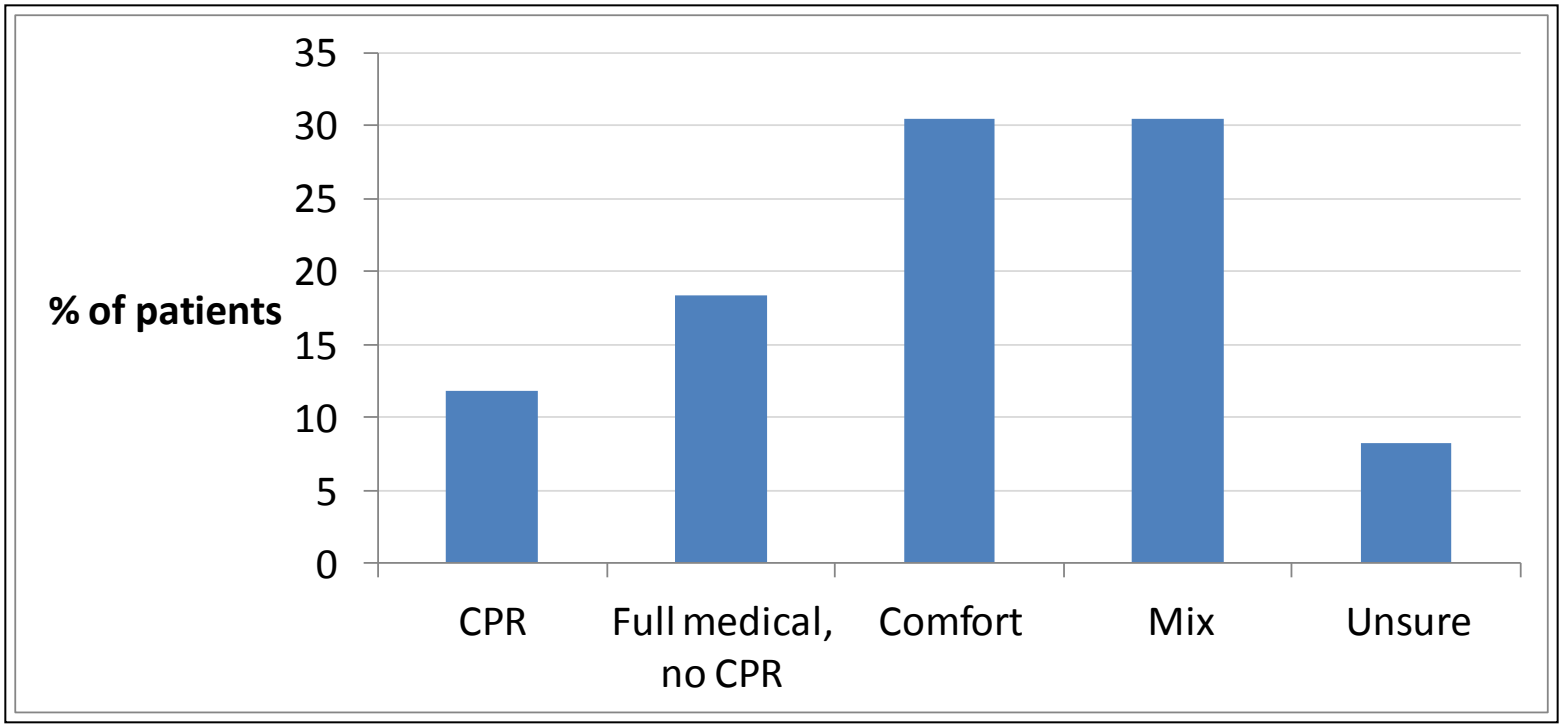
Heyland DK et al. JAMA Intern Med 2013.

ACCEPT Study Design

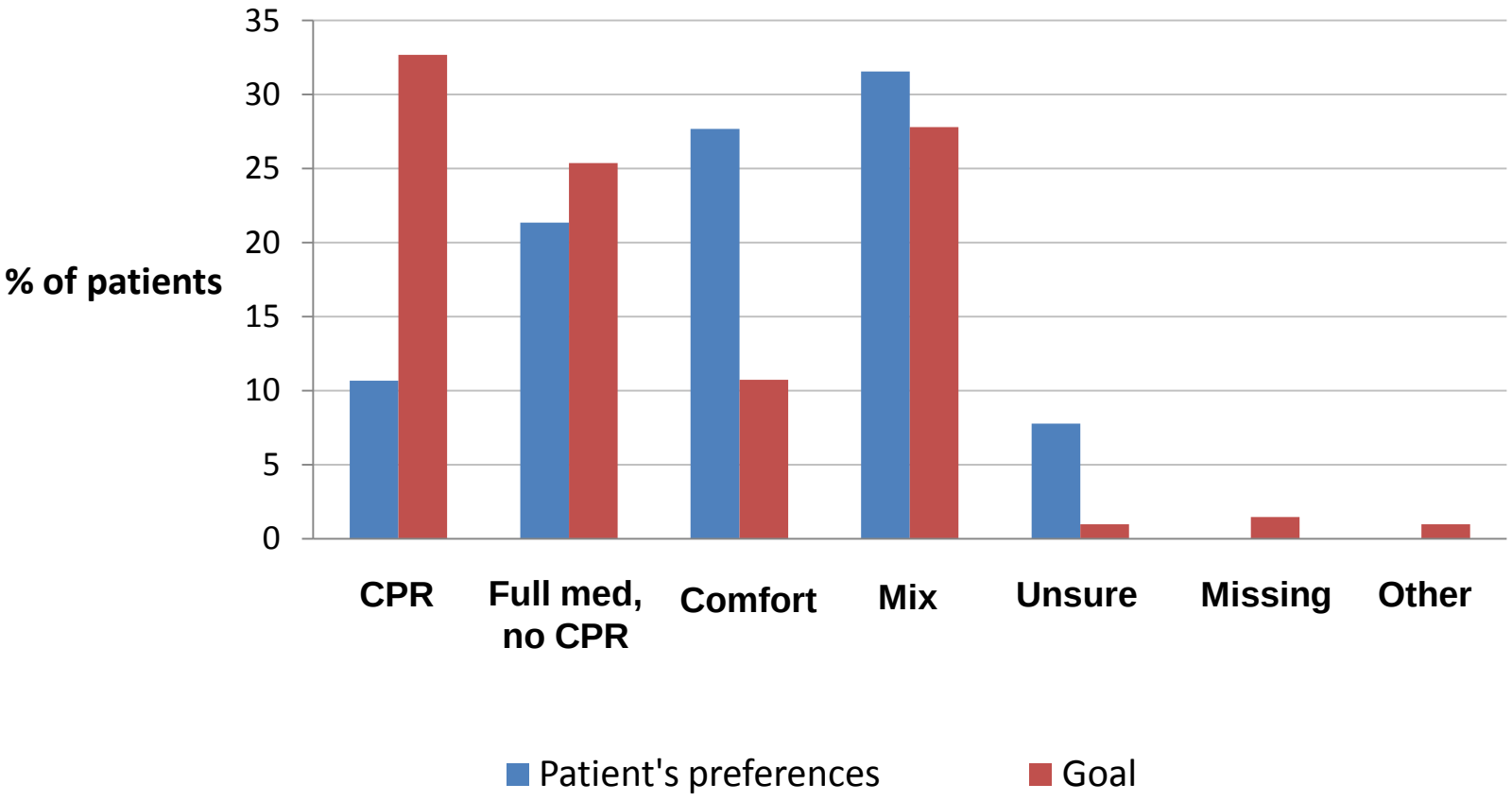
- **Setting:**
  - 12 acute care hospital sites across Canada
- **Participants:**
  - Elderly patients at high-risk of dying
    - 80 years of age or older **OR**
    - clinical indicators of advanced disease **OR**
    - "Surprise Question"
  - Family members
  - Target sample of 30 patients and 30 family members per site

Patient preferences for EOL care

- 76% of patients have thought about the kinds of life-sustaining treatments they would want
- 89% of these patients have discussed with someone



Documented goals of care are discordant with patient preferences 70% of the time



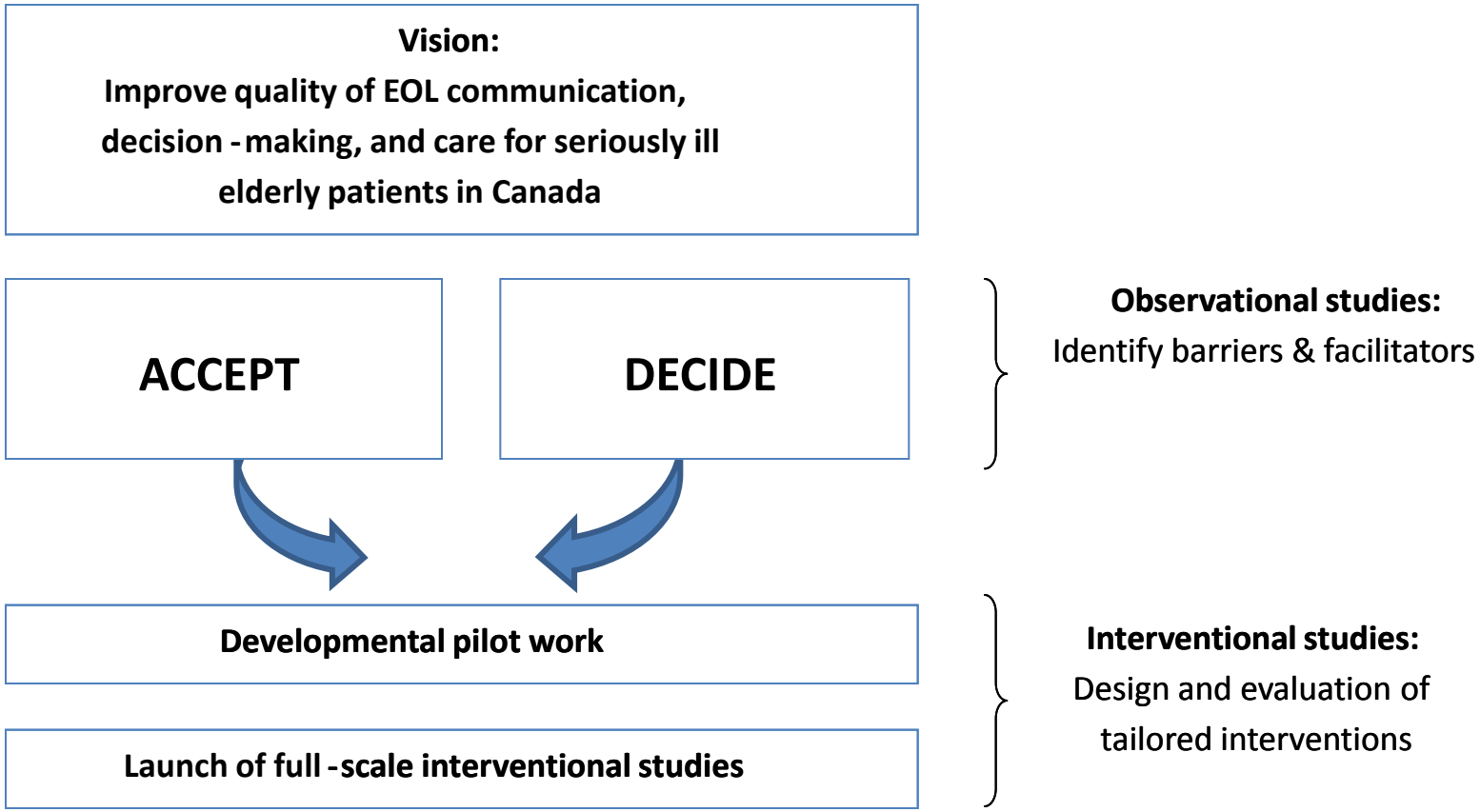
Who do seriously ill patients talk to about their end-of-life wishes?

- Of patients who have discussed EOL wishes:
  - 92% with family member
  - 30% with lawyer
  - 30% with family physician
  - 17% with specialist physician

Summary of ACCEPT findings

- High risk patients have thought about EOL wishes, talked to family members, but little engagement by healthcare providers
- Appreciable discordance between patient preferences and documented goals of care

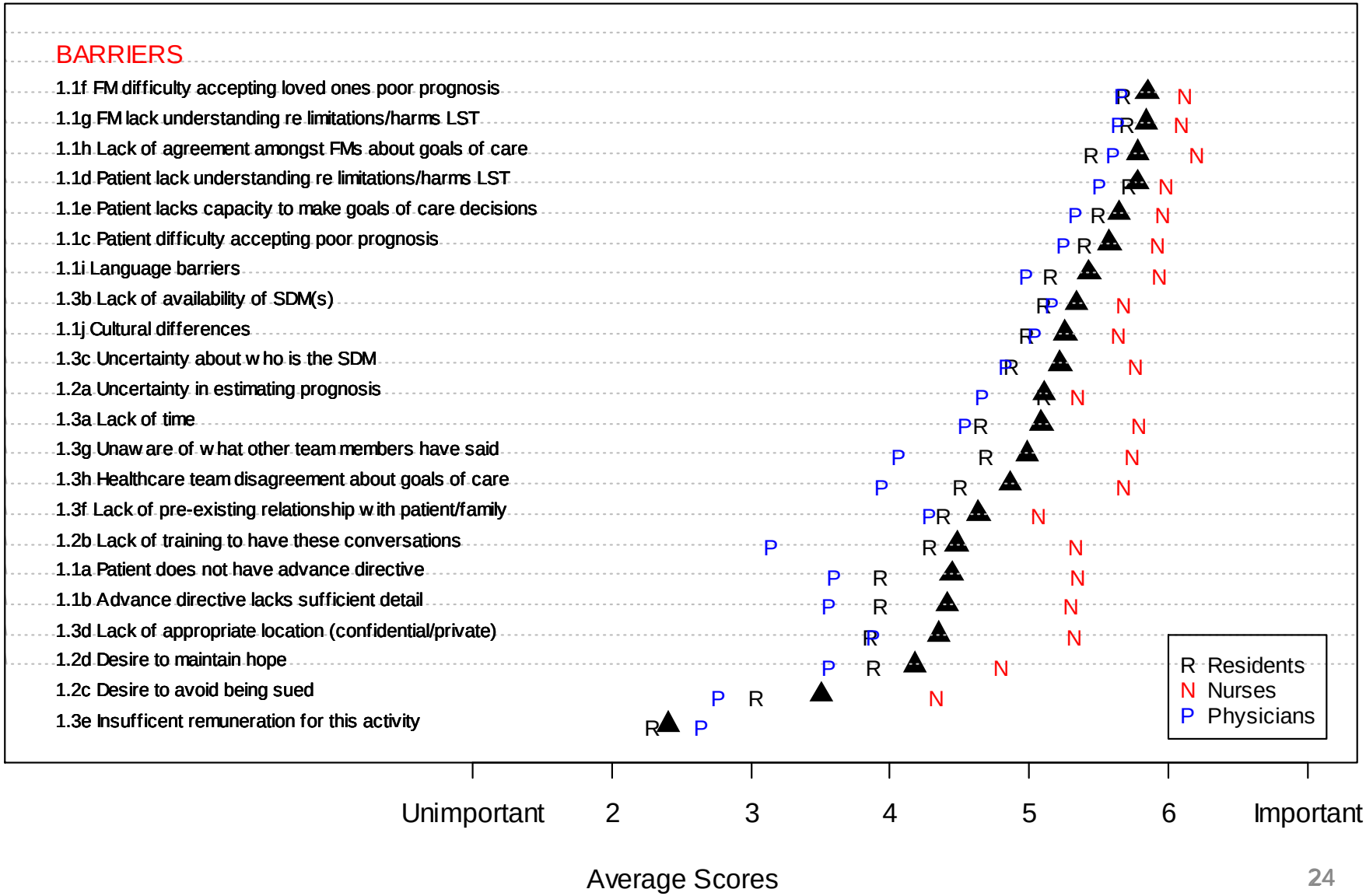
Program of research



DECIDE Study

- Multi-centre mixed-methods study
  - Questionnaires
  - Semi-structured interviews
- Medical teaching units at 13 Canadian hospitals
- To understand:
  - Barriers impeding EOL communication
  - Potential innovative solutions
  - Potential roles of interprofessional team

Barriers to goals of care discussions



A patient speaking about barriers to EOL discussions with physicians:

“I don't think they want to talk about it. It is a science based profession, and that discussion is philosophical and sociological or spiritual and does not come with a white coat.”

Real ending of Mrs W's story

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- Dec-Jan 2013: 25 day CTU admission for CHF, "deconditioned", discharged to "Assess and Restore" program with plan for retirement home (18 meds on discharge)
- Feb 2013: 4 day CTU admission for CHF. Died.

Thank you

- ACCEPT and DECIDE team members
- CERU staff
- CARENET
- Funders:
  - Canadian Institutes for Health Research
  - Alberta Innovates
  - Michael Smith Foundation (BC)
  - HAHSO AFP Innovation Fund (Ontario)

Future complex intervention

Barrier	**Potential intervention**
Patient/family lack of understanding of life-sustaining technologies	Decision aids (web, video)
Lack of access to doctor/healthcare provider	Trained ACP facilitators
Lack of prognostic disclosure	Prognostic tools (e-prognosis)
Lack of engagement by healthcare professionals	Healthcare provider communications skills training
Lack of clear documentation of values and EOL care plans	Level of care forms which include text stating patient values; “cloud”-based registry of ACP documents

Participating sites

	Hospital Names	Number of Patients	Number of Family Members
1	**Kingston General Hospital**	33	33
2	**University Health Network Toronto General Hospital**	16	21
3	**Centre hospitalier universitaire de Sherbrooke**	12	8
4	**Royal Alexandra Hospital**	11	7
5	**Rockyview Hospital**	37	23
6	**Foothills Hospital**	31	12
7	**Peter Lougheed Hospital**	19	4
8	**Vancouver General Hospital**	20	21
9	**Burnaby Hospital**	22	24
10	**Royal Columbian Hospital**	26	21
11	**St Paul's Hospital**	24	23
12	**Hamilton Health Sciences Centre**	31	29
	TOTAL	**278**	**225**