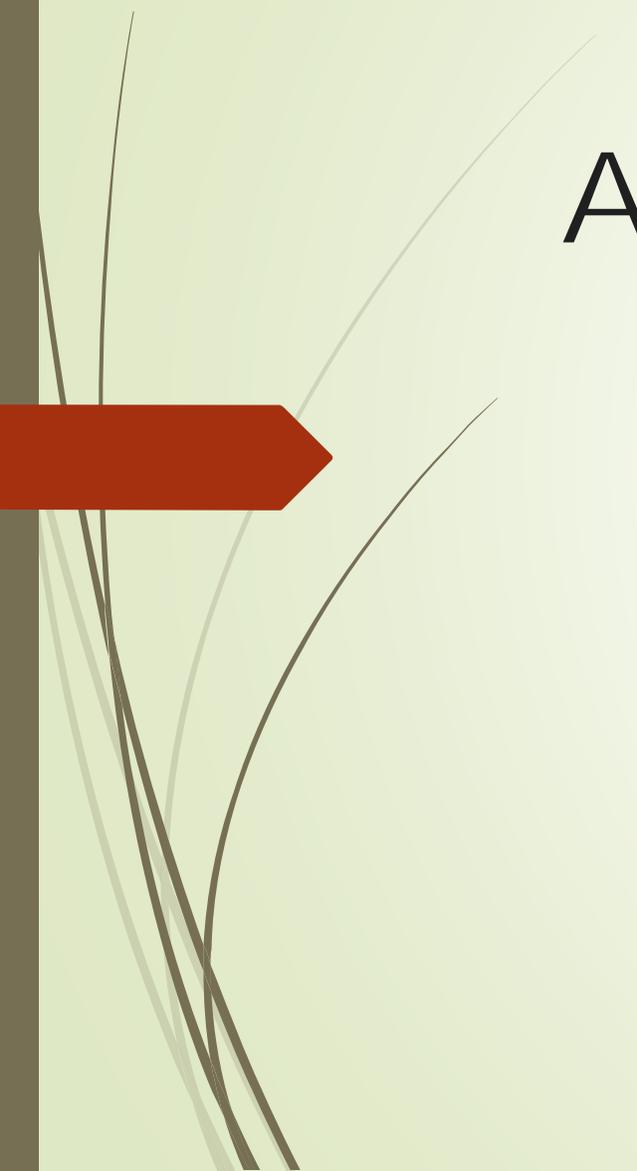


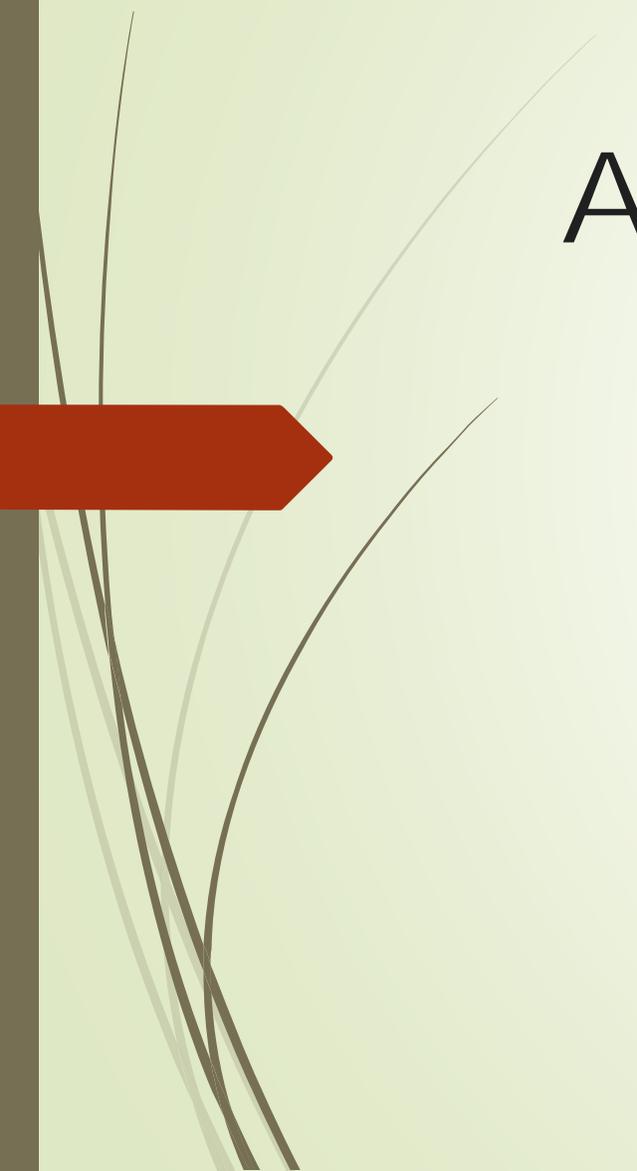
# “It’s Just Part of Life”

## Patient Acceptance of Distribution of Advance Care Planning Materials at Hospital Admission

Wrigley H MD, Standerwick L BSc, Chan T MD, Ghosh S PhD Pstat,  
Simon J MB ChB

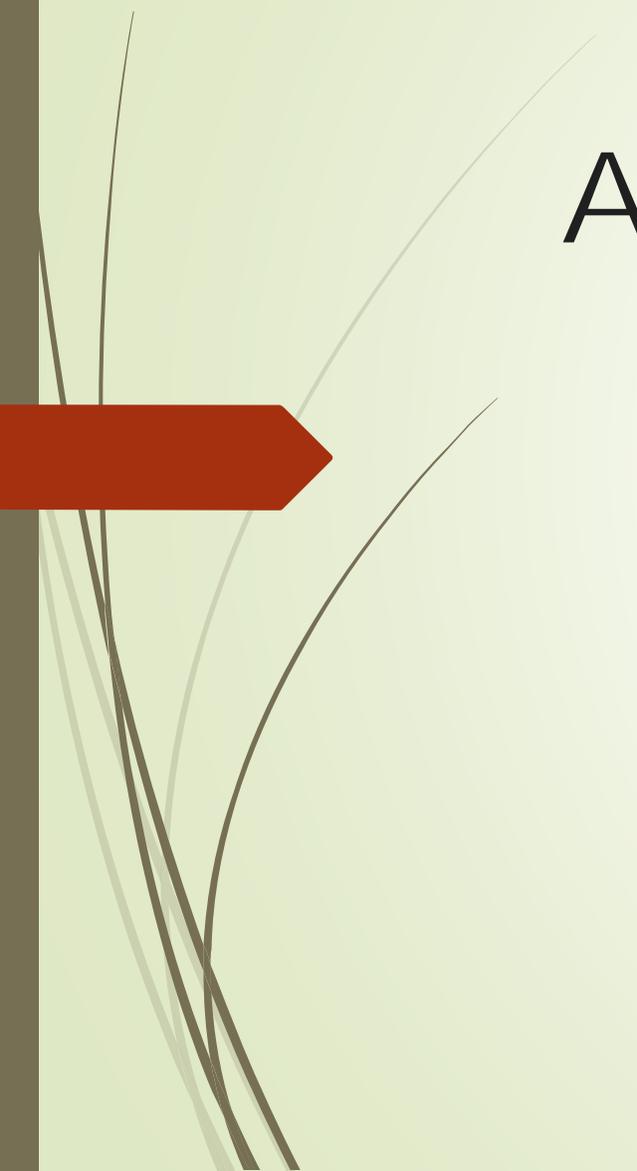


A question for the audience:

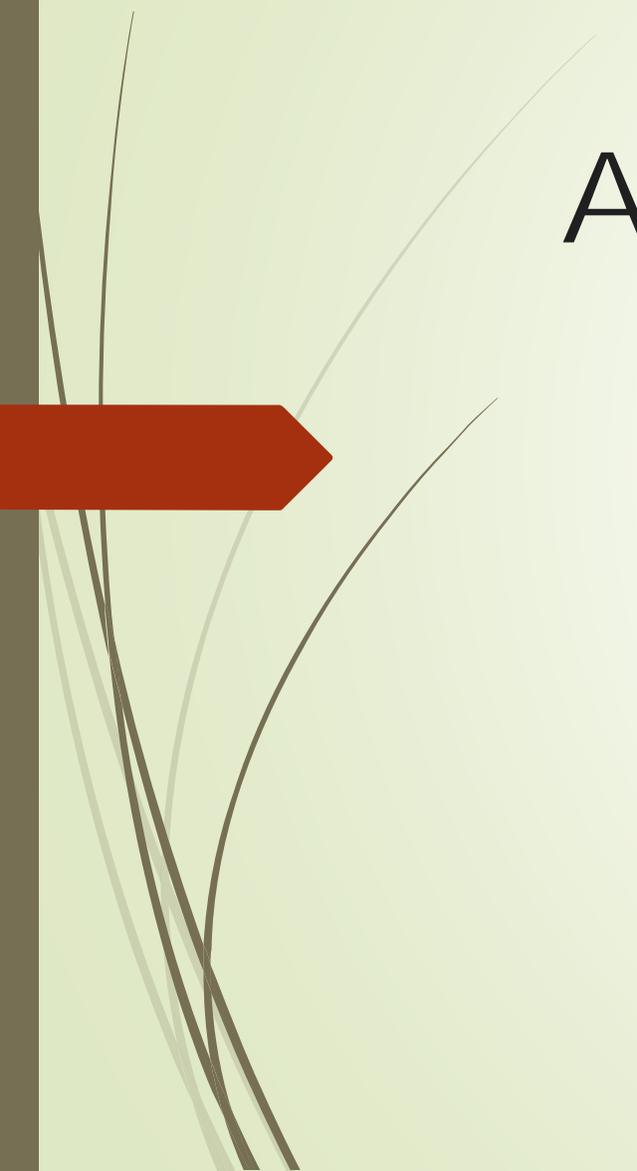


A question for the audience:

Do YOU have a personal  
directive ('living will')?



A more interesting question:



A more interesting question:

Are you upset that  
I asked?



# The Facts:

- Up to 76% of dying patients will be unable to participate in some or all of their care decisions at the end of life.<sup>1,2</sup>



# The Facts:

- Advance care planning can increase compliance with patients' end-of-life wishes and improve their care.<sup>2,3,4,5,6</sup>



# The Facts:

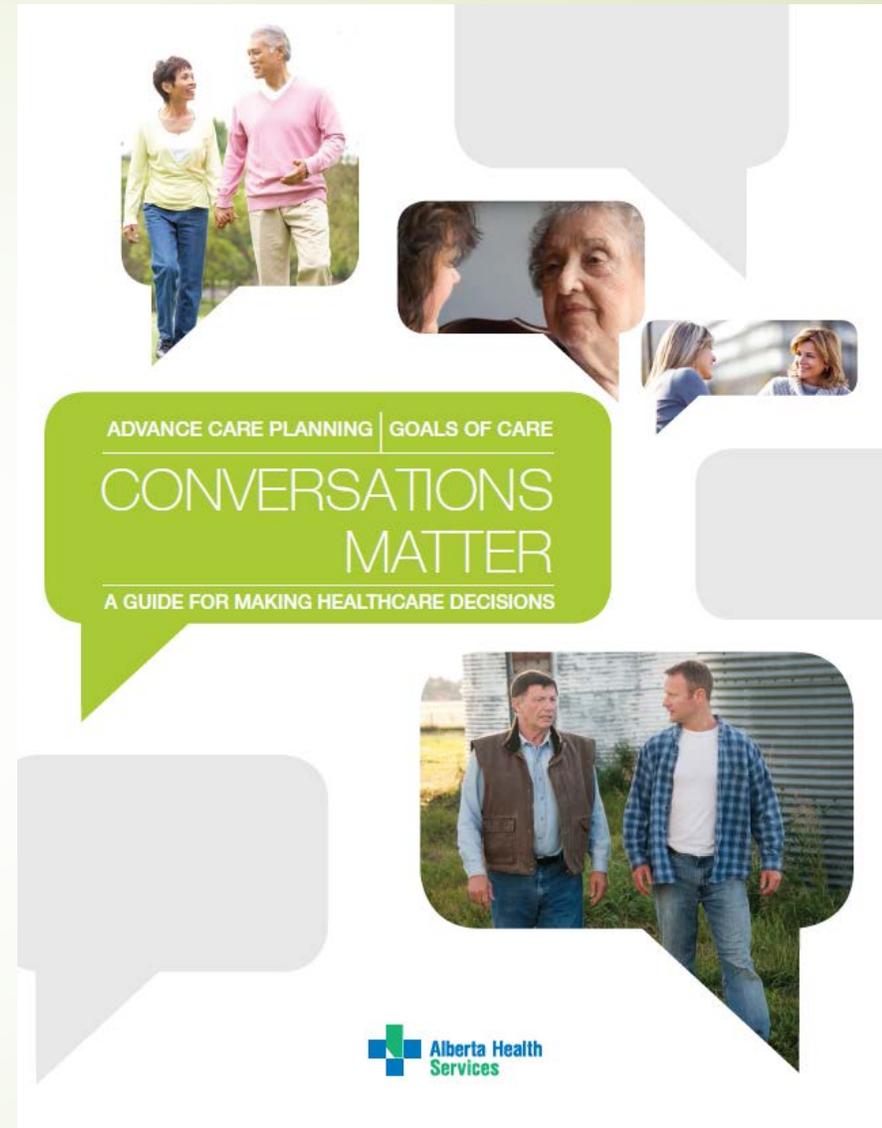
- Public and patient surveys show that many adults have not done advance care planning.<sup>4,6,8,9,10</sup>



# The Facts:

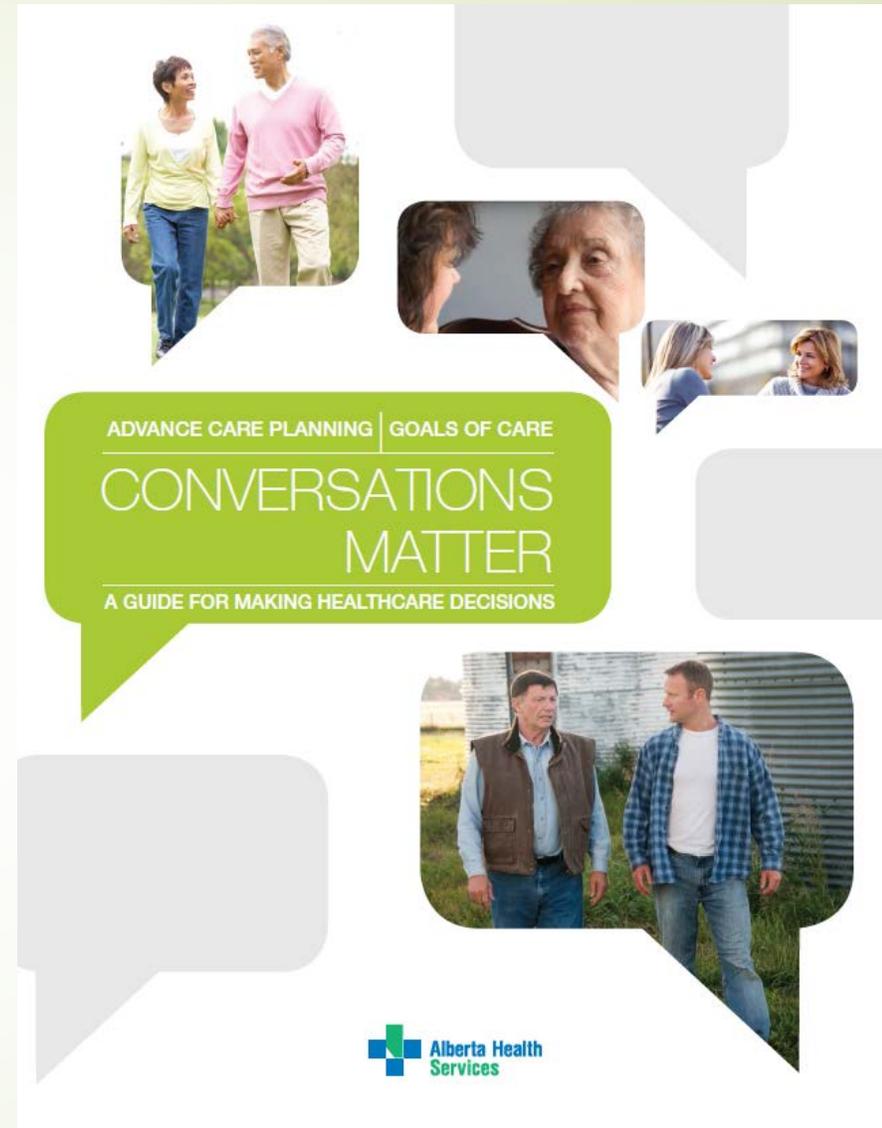
- Surveys of health care providers show that we do not bring up ACP, partly because we fear that patients will find it upsetting.<sup>6,11</sup>

Alberta Health Services  
developed this booklet for the  
public, to help educate them  
about Advance Care Planning...



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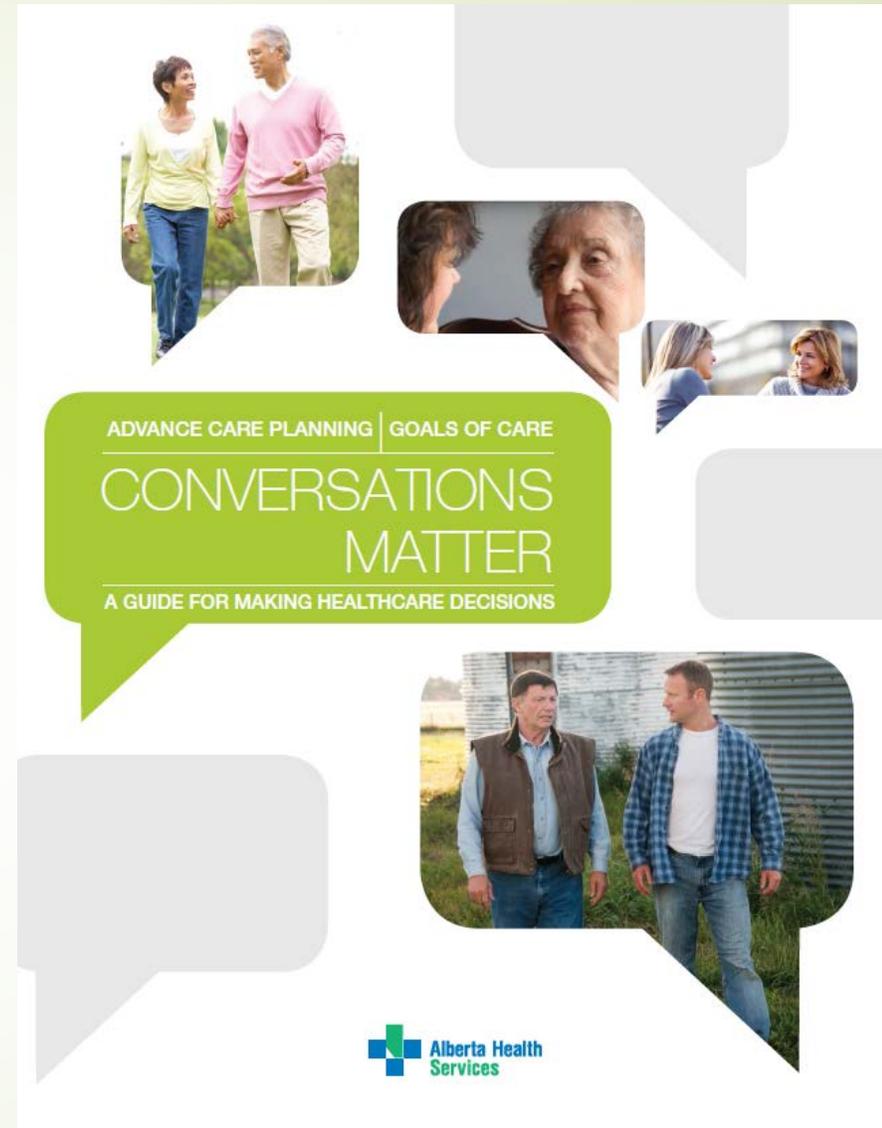
**BUT...**



Alberta Health Services developed this booklet for the public, to help educate them about Advance Care Planning...

BUT...

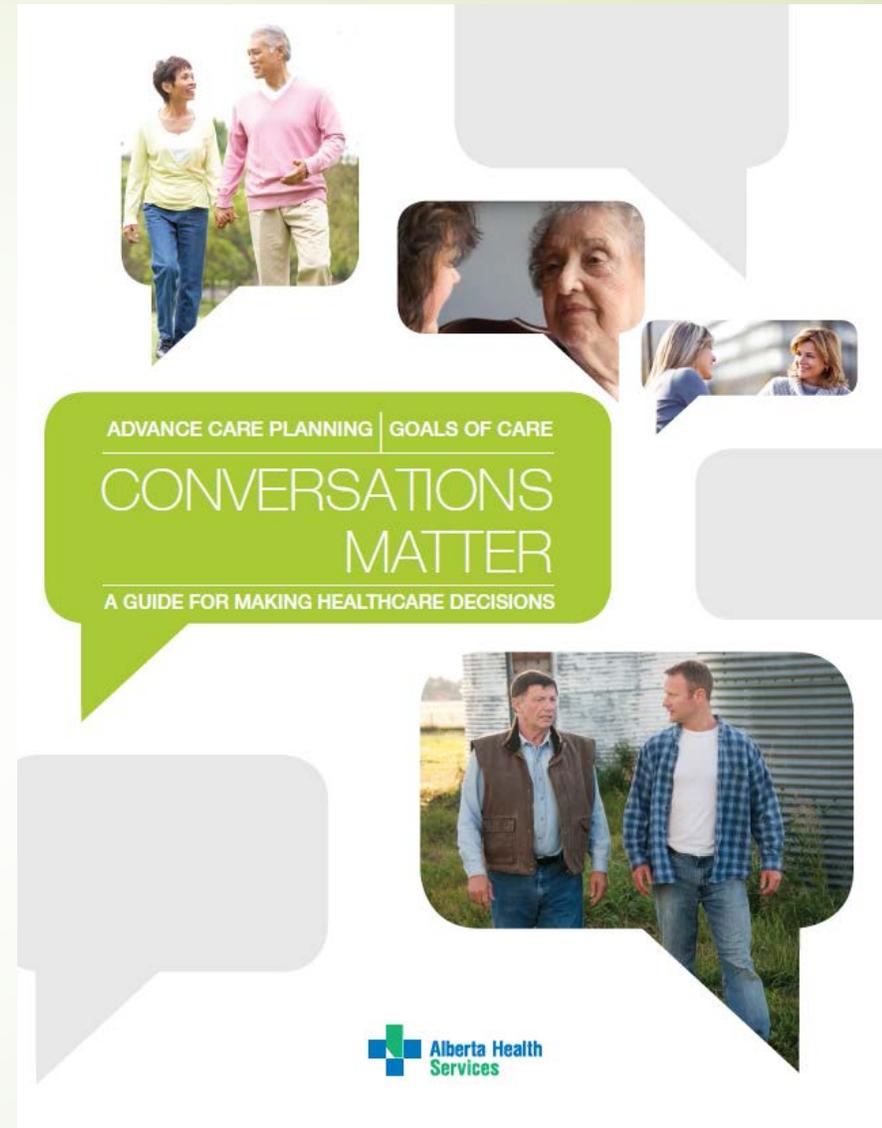
the *Conversations Matter* guidebook is not routinely given to Alberta patients at the time of a hospital admission

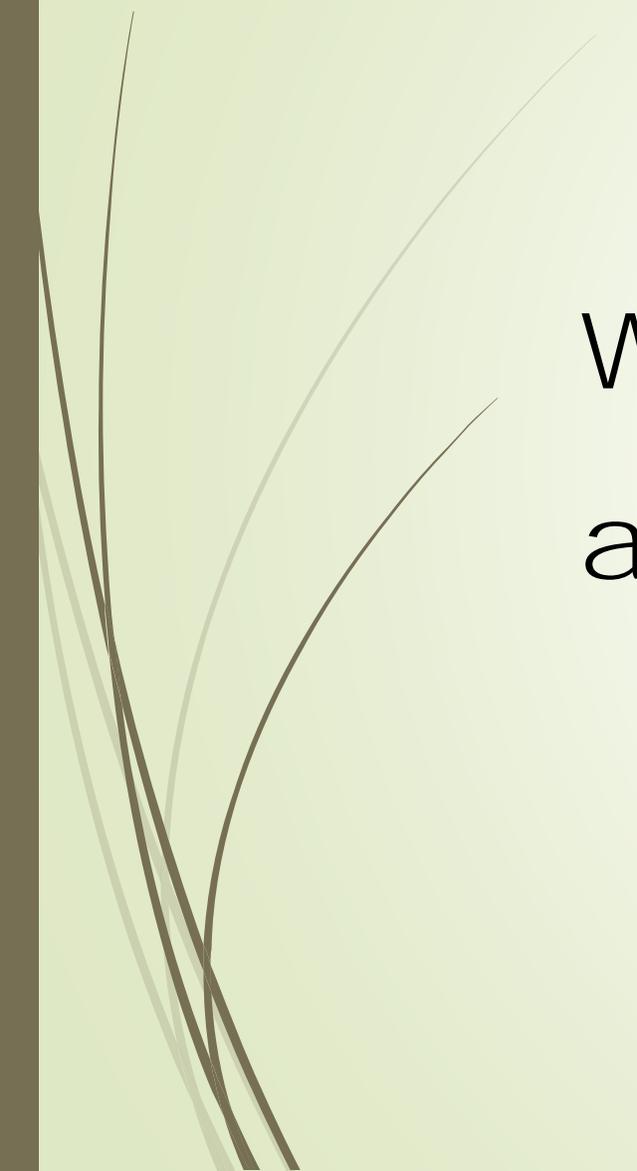


Alberta Health Services developed this booklet for the public, to help educate them about Advance Care Planning...

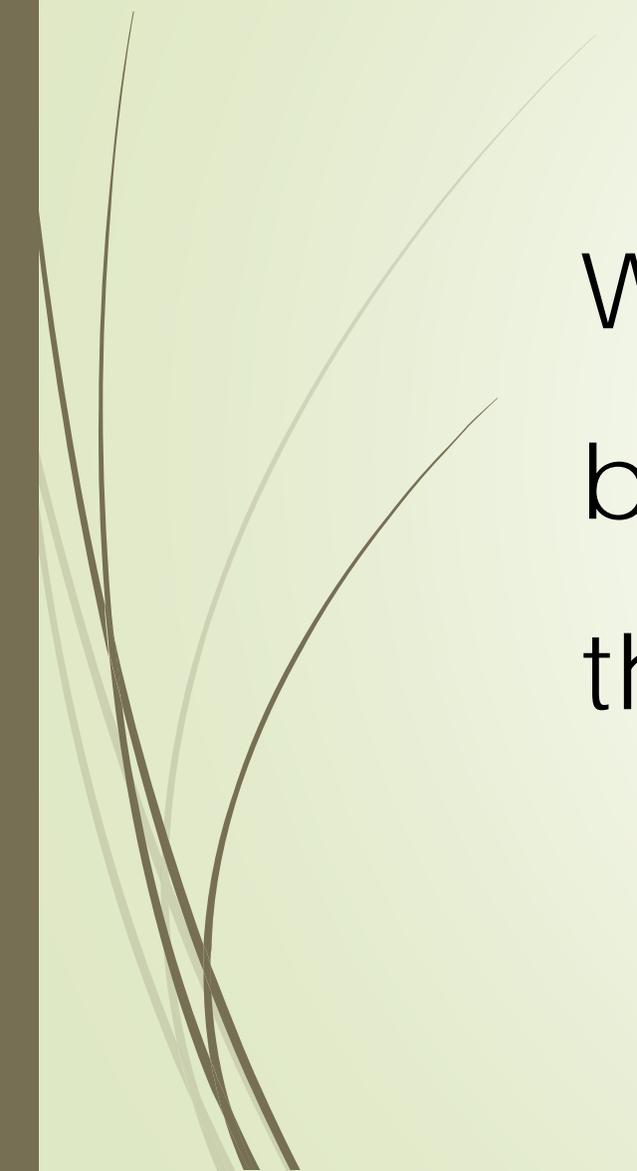
BUT...

the *Conversations Matter* guidebook is not routinely given to Alberta patients at the time of a hospital admission- **possibly in part because providers fear that it might upset patients.**





We wanted to know if there was  
any grounds for that concern.



We proposed to hand out the booklet to hospital inpatients, and then ask how they felt about it.



# Methods:

- February and March 2015
  - FMC Unit 46 (hospitalist, oncology, medicine) & FMC Unit 62 (medicine)
  - 100 patients
- 



# Exclusion Criteria:

- current cognitive impairment
- insufficient English fluency to understand the survey or answer the questions



# The Protocol:

- ▶ patients received the booklet at admission
- ▶ researcher visited units daily to identify new patients
- ▶ researcher approached bedside nurse to ask about patients' English fluency and cognition
- ▶ if appropriate, nurse asked patient if they were willing to meet researcher



# The Protocol:

- researcher explained study and got consent
- researcher asked if patient had read booklet
- if yes: administered survey verbally
- if no: offered to read booklet to them, then administered survey afterward OR
- encouraged patient to read booklet, and returned another day to do survey



# Sample Size:

- descriptive study
- population of both units ~76 patients
- assumed margin of error: 6%
- desired confidence level: 95%
- minimum participants needed: 60



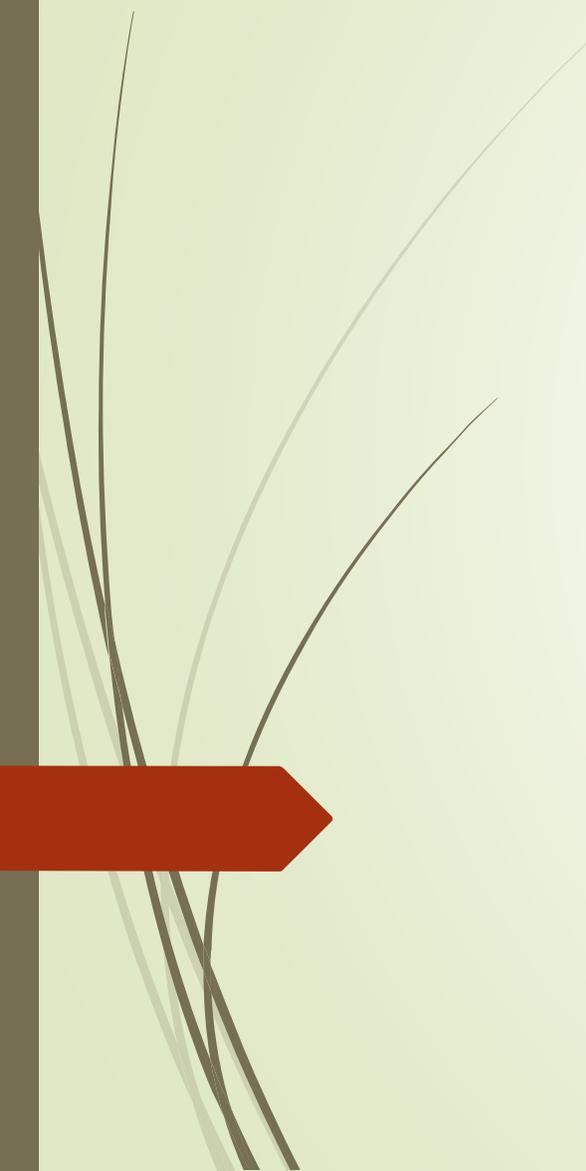
# Ethics:

- Approved by the University of Calgary  
Conjoint Health Research Ethics Board
  - REB certification REB14-1176
- 



# Our participants:

- 100 patients
- Age range 22 to 98 (mean 70)
- 40% female; 60% male



**The results...**



Quantitative questions  
(Likert scale):



How much of the *Conversations  
Matter* booklet did you read?

I didn't read any of it, or I don't know  
or don't remember

I skimmed it

I read about half of it

I read most of it

I read the whole thing

# How much of the *Conversations Matter* booklet did you read?

I didn't read any of it, or I don't know or don't remember: **0%\***

I skimmed it: **27%**

I read about half of it: **11%**

I read most of it: **13%**

I read the whole thing: **49%**



How helpful did you think the booklet was?

It was completely useless

It was a tiny bit helpful

It was somewhat helpful

It was quite helpful

It was extremely helpful

I don't know or don't remember

# How helpful did you think the booklet was?

It was completely useless: **2%**

It was a tiny bit helpful : **2%**

It was somewhat helpful : **6%**

It was quite helpful: **31%**

It was extremely helpful: **54%**

I don't know or don't remember: **5%**



How did you feel when you read the booklet?

I wasn't upset by it at all

It made me a tiny bit upset

It made me somewhat upset

It made me quite upset

It made me extremely upset

I don't know or don't remember

# How did you feel when you read the booklet?

- I wasn't upset by it at all: **88%**
- It made me a tiny bit upset: **9%**
- It made me somewhat upset: **1%**
- It made me quite upset: **0%**
- It made me extremely upset: **1%**
- I don't know or don't remember: **1%**

What do you think about the idea of giving this guidebook out to everybody who comes into the hospital?

I think giving it to everyone is a great idea

I think it's okay to give it to everyone

I don't think it matters one way or the other

I don't think it's okay to give it to everyone

I think giving it to everyone is a terrible idea

I don't know

What do you think about the idea of giving this guidebook out to everybody who comes into the hospital?

I think giving it to everyone is a great idea: **65%**

I think it's okay to give it to everyone: **21%**

I don't think it matters one way or the other: **1%**

I don't think it's okay to give it to everyone: **9%**

I think giving it to everyone is a terrible idea: **3%**

I don't know: **1%**



Qualitative questions:

May I ask why you chose that answer?

Should give to all because ACP is important: **24%**

Some might be upset, but shouldn't be: **17%**

Should give only (or especially) to older people: **16%**

Should give only to people with serious illness: **8%**

Giving to everyone is harmless: **7%**

May I ask why you chose that answer?

Give to all; they can decide to read or not: **6%**

Many people won't read it: **6%**

Giving to all is wasteful (of paper or money): **3%**

Should give both in and outside of hospital: **2%**

Should not give to all because not useful: **1%**

Do you have any other thoughts?

The guidebook is informative: **27%**

Advance care planning is important: **21%**

People shouldn't be upset re: discussing ACP: **17%**

ACP is just part of life and/or adulthood: **17%**

Doing ACP is appropriate for people of all ages: **6%**

# Do you have any other thoughts?

Doing advance care planning is interesting: **5%**

Communicating your wishes is important: **5%**

Doing ACP can give you peace of mind: **4%**



# Statistical Analysis:

- A Pearson chi-square test found no age or gender differences between any of the responses.



## Discussion:

- ▶ Patients were accepting of advance care planning materials
- ▶ Patients found the ACP materials helpful
- ▶ Most were in favour of routinely distributing them to all patients
- ▶ A sizeable minority suggested targeted distribution instead



## Discussion:

- ▶ Our findings are consistent with the results of similar studies in the U.S.<sup>15</sup> and U.K.<sup>14</sup>
- 



## Discussion:

- Our study found a belief among some patients that ACP is only appropriate for those who are elderly or dying

*but interestingly,*

- Our actual data suggest that receipt of ACP information is not upsetting to patients regardless of their age



# Potential Sources of Bias:

- ▶ Selection bias
  - ▶ Social desirability bias
- 



# Generalizability:

- Age: Our participants were older than the general population
- Exclusion criterion: lack of English fluency
- Population sampled: medical inpatients

## However...

- Our findings closely replicated those of similar studies in the USA and the UK, which suggests that the results are probably generalizable across developed, English-speaking countries



## Limitations:

- This study did not attempt to evaluate the efficacy of distributing ACP materials in promoting ACP participation
- We can say that the materials are acceptable to patients, but we cannot say whether they are effective



## Strengths:

- Inclusion of qualitative questions
  - Results replicated those found in other jurisdictions using different ACP materials, so the results are likely to be generalizable to different populations and different ACP materials
- 



# Acknowledgements:

We are grateful to:

- management, nursing and clerical staff of Units 46 and 62 at Foothills Hospital
- patients who participated
- Patricia Biondo, PhD, Research Manager with the ACP-CRIO program
- Alberta Innovates- Health Solutions, who provided funding for this project as part of the ACP-CRIO grant



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