

Site Report

Advance Care Planning Evaluation in Elderly Patients: A multicenter, prospective study. The ACCEPT Study

SITENAME Audit Cycle #1 (2011)

Produced by:

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Interpreting Your Site Report

The ACCEPT Study is an observational survey study geared towards informing decision-makers as to the best strategies to implement advance care planning (ACP). The primary objective of this study is to determine, from patient and family members perspectives, the prevalence of ACP and its various components, satisfaction with end of life communication and decision-making, and what barriers there are to improving the quantity and quality of ACP.

Your site has been conducting interviews with both patients and their family members for this study. This site report summarizes the findings of these interviews at ('Site') and will allow you to compare them with data from all participating sites ('All').

The first couple of pages of this report relate to information collected in Section 1 of the ACP questionnaire. They describe the characteristics of respondents (both patients and family members) involved in this study. This demographic data will help you to identify any similarities and differences in the structure and patient case-mix of your site compared to other sites and will help you to interpret your site report in context in which you work.

Subsequent pages summarize the questionnaire data, as it relates to decisions made about healthcare prior to hospital admission, decisions made about healthcare during the index hospitalization, goals of care, overall satisfaction (CANHELP) and corresponding documentation present in the patient's medical record at the time of interview.

These data will compare and contrast your local hospital results to those of all hospitals participating in this initiative.

Glossary of Terms

Pt: This denotes patient respondent data.

FM: This denotes family member respondent data.

Your site: This represents the mean of all data from your site. This is depicted in figures using the 'clear' block. All sites: This represents the mean of all data from all sites in the database. This is depicted in

figures using the 'diamond'and 'range bars.'

Diamond: This denotes the average response across all sites.

Range bars: This denotes the site with the 'highest' and 'lowest' average across all sites.

%: Percent

n/N: Number of observations at your site/all sites

Legend of tables and figures in the report

Sample Figure

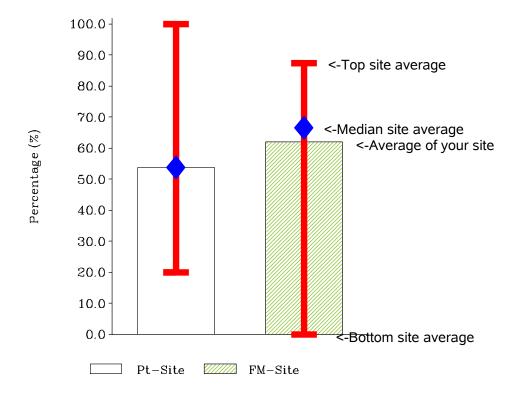
PT (site)	PT (all sites)	FM (site)	FM (all sites)
n=31	n=279	n=12	n=226

n for PT(site) refers to the total number of patients with available data from your site.

n for PT(all sites) refers to the total number of patients with available data.

n for FM(site) refers to the total number of family members with available data from your site.

n for FM(all sites) refers to the total number of family members with available data.



Sample Table

	PT(site)	PT(all sites)	FM(site)	FM(all sites)
RESPONSES	n=30	n=158	n=11	n=100
Goals of Care designation or MOST	4.5%	3.9%(0.0, 0.0, 33.3)	11.1%	3.7%(0.0, 0.0, 16.7)
My voice documents	4.5%	1.6%(0.0,0.0,20.0)	0%	0.9%(0.0, 0.0, 20.0)
Respecting Choice	0%	0.8%(0.0, 0.0, 5.9)	0%	-

Legend

% (x,y,z): % is the proportion of patients/family members that reported 'yes' to type of tool used;

x is the site with the median proportion of patients/family members reported 'yes';

y is the site with the lowest proportion of patients/family members reported 'yes';

z is the site with the highest proportion of patients/family members reported 'yes'.

SECTION 1: Patient/Family Member Demographics

Number of patient	Patient Characteristics Your Site n=24	All Sites n=279
Age mean(range)(n)	82.3(59.0-99) (24)	80.0(55.0-99) (279)
Sex Male Female	12 (50.0%) 12 (50.0%)	132 (47.3%) 147 (52.7%)
Marital Status (currently) Married or living as married Widowed Never married Divorced or separated; not remarried	5 (20.8%) 10 (41.7%) 5 (20.8%) 4 (16.7%)	100 (35.8%) 124 (44.4%) 18 (6.5%) 37 (13.3%)
Last location of living in last month(If in hospital then month prior to hospitalization) Other (specify) Home (or other private dwelling)	0 14 (58.3%)	1 (0.4%) 103 (36.9%)
alone Home (or other private dwelling) with spouse or significant other Home (or other private dwelling) with children or other family	6 (25.0%) 1 (4.2%)	90 (32.3%) 34 (12.2%)
members Retirement Residence Long Term Care or Nursing Home Rehabilitation Facility	2 (8.3%) 1 (4.2%) 0	36 (12.9%) 14 (5.0%) 1 (0.4%)
Caucasian respondents n/N (%)	24/24 (100%)	263/279 (94.3%)
Caucasian and speak another language on a daily basis n/N (%)	3/24 (12.5%)	48/279 (17.2%)
Non-caucasian and speak another language on a daily basis n/N (%)	0/24	9/279 (3.2%)

Legend n: number of patients/family members reported 'YES' N: total number of patients/family members %: Percentage

SECTION 1: Patient/Family Member Demographics

I	Family Member Characteristics	
Number of patient	Your Site n=23	All Sites n=223
Age mean(range)(n)	60.9(25.0-85) (23)	60.8(20.0-92) (223)
Sex Declined Male Female	0 9 (39.1%) 14 (60.9%)	1 (0.4%) 54 (23.9%) 171 (75.7%)
Relationship to patient Other (specify) Spouse/Partner Parent Parent-in-law Daughter/Son Sister/Brother	$\begin{array}{c}3\ (13.0\%)\\6\ (26.1\%)\\2\ (8.7\%)\\1\ (4.3\%)\\11\ (47.8\%)\\0\end{array}$	$\begin{array}{c} 13 \ (5.8\%) \\ 78 \ (34.5\%) \\ 3 \ (1.3\%) \\ 3 \ (1.3\%) \\ 127 \ (56.2\%) \\ 2 \ (0.9\%) \end{array}$
Education - highest level achieved Declined Elementary school or less Some high school High school graduate Some college (including CEGEP) / trade school College diploma (including DEC) / trade school	0 0 4 (17.4%) 5 (21.7%) 3 (13.0%)	2 (0.9%) 7 (3.1%) 26 (11.5%) 41 (18.1%) 29 (12.8%) 42 (18.6%)
Some university University degree Post Graduate	3 (13.0%) 5 (21.7%) 3 (13.0%)	12 (5.3%) 48 (21.2%) 19 (8.4%)
Respondent is the subtitute		
decision maker n/N (%)	17/23 (73.9%)	190/223 (85.2%)
Relative is mentally competent n/N (%)	11/23 (47.8%)	171/223 (76.7%)
Caucasian respondents n/N (%)	15/23 (65.2%)	192/223 (86.1%)
Caucasian and speak another language on a daily basis n/N (%)	3/23 (13.0%)	48/223 (21.5%)
Non-caucasian and speak another language on a daily basis n/N (%)	6/23 (26.1%)	21/223 (9.4%)

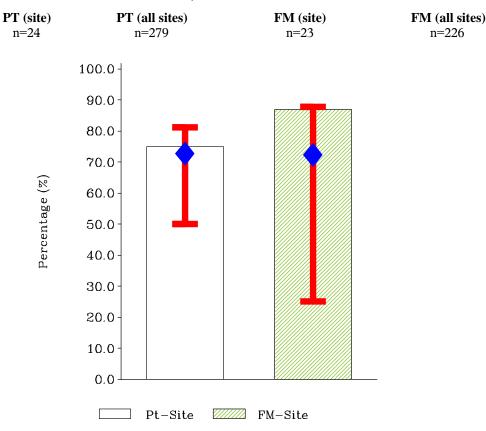
Legend

n: number of patients/family members reported 'YES' N: total number of patients/family members %: Percentage

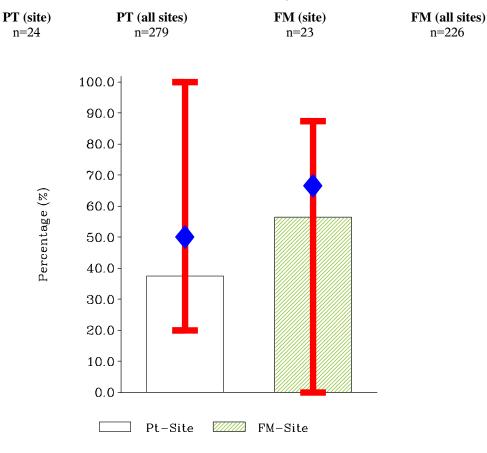
Other languages Caucasian speak on a daily basis No data for this question from this site

Other languages Non-caucasian speak on a daily basis No data for this question from this site

Q1 - Proportion of patients with a formally designated representative concerning treatment decisions (eg. Power of Attorney for Health or Substitute Decision-Maker)



Q2 - Proportion of patients that have an advance directive/living will/some other written document.



2a) If yes, what type of tool was used?

RESPONSES	PT(site) n=7	PT(all sites) n=127	FM(site) n=11	FM(all sites) n=109
Goals of Care designation or MOST	0%	3.9%(0.0, 0.0, 33.3)	0%	3.7%(0.0, 0.0, 16.7)
My voice documents	0%	1.6%(0.0,0.0,20.0)	0%	0.9%(0.0, 0.0,20.0)
Respecting Choice	0%	0.8%(0.0, 0.0, 5.9)	0%	-
Generic Living will or Advance Directives	28.6%	59.8%(64.2, 5.0, 100)	54.5%	50.5%(66.7, 0.0, 100)
DNR or DNAR or NO CPR form	0%	3.9%(0.0, 0.0, 27.3)	27.3%	12.8%(8.3, 0.0,60.0)
Other	71.4%	33.9%(24.3, 0.0,95.0)	45.5%	44%(33.3, 0.0, 100)

'Other' type of tools reported by patients

ID	Open text (n=5)
10251021	Went to Notary Public and lawyer for Power of Attorney
10251025	Went to a lawyer
10251029	Went to a lawyer - a special will that cannot be broken by anyone
10251041	Don't remember
10251043	notary public

'Other' type of tools reported by family members

ID	Open text (n=5)
10251002	group of lawyers that have documents 'My Living Will', Power of Attorney, 'My Last Wishes'- 3 in 1
	documents? possibly one more
10251003	medical form-advanced care directive
	No tools, just went to lawyer
	Family discussion, she wrote out wishes
10251043	notary public

2b) If no, why not?

		PT(site)	PT(all sites)
Domains	Questions	n=4	n=59
Patient Factors	It is not relevant to me at this time	1 (25.0%)	13.6%(15.7, 0.0,50.0)
	I have not thought about it	1 (25.0%)	27.1%(25.0, 0.0,60.0)
	I have not made the time for it	0(0.0%)	11.9%(10.6, 0.0,50.0)
	I am not comfortable thinking about or	0(0.0%)	13.6%(10.1, 0.0,60.0)
	talking about dying		
Family Factors	I trust my family to make the right	2 (50.0%)	49.2%(50.0,20.0,90.0)
	decision when the time comes		
Doctors Factors	I trust the doctor to make the right	2 (50.0%)	18.6%(33.3,18.2,50.0)
	decision when the time comes		
Process Factors	I do not know where to access such	2 (50.0%)	10.2%(41.7,22.2,50.0)
	documents		
	I dont know which document to use	0(0.0%)	1.7%(0.0, 0.0,11.1)

Domains	Questions	FM(site) n=1	FM(all sites) n=35
Patient Factors	S/He trusts me to make the right decision when the time comes	1 (100%)	42.9%(57.1,14.3, 100)
Family Factors	It is not relevant to us at this time	-	8.6%(0.0,0.0,28.6)
	We have not thought about it	-	25.7%(17.2, 0.0,66.7)
	We have not made the time for it	-	20%(22.5, 0.0, 100)
	We are not ready to discuss these matters at this time	-	11.4%(0.0, 0.0,66.7)

Domains	Questions	FM(site) n=1	FM(all sites) n=35
	We do not think they are important or useful	-	5.7%(0.0, 0.0,33.3)
Doctors Factors	We trust the doctor to make the right decision when the time comes	-	11.4%(41.7,20.0, 100)
Process Factors	We do not know where to access such documents	0(0.0%)	5.7%(20.0, 0.0, 40.0)
	We don't know which document to use	1 (100%)	2.9%(50.0, 0.0, 100)
	We are confused about their legal status	0(0.0%)	2.9%(10.0, 0.0,20.0)

3a) Proportion that have ever considered/thought about what kinds of life-sustaining treatments (CPR, breathing machines, dialysis, ICU admission, etc.) would (not) want in the event your (relative's) physical health deteriorated?

Q3a Verbal Response from the patients

ID	Open text (n=6)
	I dont know what conditon I'd have to be in to need those things.
	Didn't have the opportunity
10251031	I hadn't thought about dying and what happens to my soul. Taxonomy- I am not ready to think about it, I
	am not comfortable thinking about dying, I trust my doc to make the right decision when the time comes,
	I trust my fa to make the right decision when the time comes.
	Never thought about it- told family wanted to be cremated when gone.
10251042	I would want to be revived if possible
10251044	Never thought about it

Q3a Verbal Response from the FM

ID	Open text (n=6)
10251006	'We just don't want her to suffer'
10251026	We never talked about it- don't want to make assumptions
10251033	Never came up
10251034	Same as last question- never before asked if thought about it.
10251035	Just didn't think about it- same as last answer.
10251043	Don't think about it. Taxonomy: I trust my doctor to make the right decision when the time comes

RESPONSES	PT(site)	PT(all sites)	FM(site)	FM(all sites)
	n=24	n=279	n=23	n=226
Yes	66.7%	76%(83.0,50.0, 100)	69.6%	81.9%(.,69.6, 100)

If no, what are your reasons?

		PT(site)	PT(all sites)
Domains	Questions	n=2	n=30
Patient Factors	It is not relevant to me at this time	1 (50.0%)	26.7%(26.7, 0.0, 100)
	I am not ready to think about this	1 (50.0%)	16.7%(0.0, 0.0,60.0)
	I have not made the time for it	0(0.0%)	30%(16.7, 0.0, 100)
	I am not comfortable thinking about dying	0(0.0%)	6.7%(0.0, 0.0, 100)
Family Factors	I trust my family to make the right decision	2(100%)	40%(63.4,14.3, 100)
Doctors Factors	I trust my doctor to make the right decision	1 (50.0%)	33.3%(40.0,14.3, 100)
Process Factors	I did not think I had the ability to influence these decisions	1 (50.0%)	10%(20.0,20.0,50.0)

		FM(site)	FM(all sites)
Domains	Questions	n=1	n=15
Family Factors	It is not relevant to me/us at this time	1 (100%)	26.7%(25.0, 0.0, 100)
	I(we)are not ready to think about this	0(0.0%)	20%(0.0, 0.0,50.0)
	right now		
	I(we)have not made the time for it	0(0.0%)	33.3%(16.7, 0.0,66.7)
	I(we)am/are are not comfortable thinking	0(0.0%)	6.7%(0.0, 0.0, 33.3)
	about dying		
	I(we)trust the family to make the right	0(0.0%)	13.3%(0.0, 0.0, 100)
	decision when the time comes		
Doctors Factors	I(we)trust her/his doctor to make the	1 (100%)	20%(100,33.3,100)
	right decision when the time comes		

-If yes, did you discuss these wishes with anyone?

RESPONSES	PT(site)	PT(all sites)	FM(site)	FM(all sites)
	n=16	n=212	n=16	n=185
Yes	87.5%	88.7%(89.6,71.4, 100)	100%	88.1%(.,64.7, 100)

% of respondents had a discussion with

	PT(site)	PT(all sites)	FM(site)	FM(all sites)
RESPONSES	n=14	n=188	n=14	n=161
Family Doctor	35.7%	30.3%(30.3,12.5,41.7)	35.7%	22.4%(21.1, 0.0,47.1)
Specialist Doctor	21.4%	17%(12.3, 0.0,48.0)	28.6%	18.6%(14.4, 0.0,60.0)
Other Doctor	7.1%	17%(13.6, 0.0,61.9)	0%	23.6%(19.5, 0.0,61.9)
Nurse	7.1%	8%(5.4, 0.0,24.0)	7.1%	9.9%(7.4, 0.0,60.0)
Social Worker	7.1%	5.3%(1.8, 0.0, 33.3)	7.1%	5.6%(4.7, 0.0,40.0)
Spiritual Care	14.3%	6.4%(4.2, 0.0,33.3)	0%	1.9%(0.0, 0.0, 15.4)
Family Member(s)/the patient	78.6%	92%(91.0,75.0, 100)	64.3%	82.6%(89.4,58.8, 100)
Surrogate Decision Maker/Other Family	42.9%	56.4%(52.8, 0.0,96.4)	85.7%	73.9%(76.6,57.7, 100)
Lawyer	14.3%	29.8%(25.0, 0.0,64.0)	7.1%	27.3%(16.7, 0.0,80.0)
Other	14.3%	2.1%(0.0, 0.0, 14.3)	14.3%	6.8%(3.0, 0.0,60.0)

3b) Reasons not discussing with a doctor ("No" in 3a.i-iii)

Q3b Verbal Response from the patients

ID	Open text (n=7)	
10251007	'It just didn't occur to me' Taxonomy responses- I trust my partner, family or surrogate decision maker	
	to make the right decision when the time comes. I have delegated that decision to someone else	
10251010	I did not see my doctor very much prior to coming to hospital. We knew everything would work out fine	
	Didn't feel it was necessary	
	The doctor didn't bring it up.	
10251021	Didn't think it was necessary and not of interest to anyone else. Never occured to me to talk about it	
	Taxonomy respones: I trust my partner, family or surrogate decision maker to make the right decision	
	when the time comes The doctor didn't ask me	
10251025	Doctors didn't bring it up and I didn't bring it up	
10251041	There was no need- taxonomy: this issue is not relevant for me at this time	

Q3b Verbal Response from the FM

ID	Open text (n=9)	
10251002	Wanted to wait until I heard what his prognosis was first and then find out about the pro's and con's of	
	various treatments. Taxonomy response I am not ready to discuss these matters at this time with his Dr.	
10251004	We don't have the knowledge at this time so we trust the doctors. Taxonomy response We trust my	
	doctor to make the right decision when the time comes.	
10251008	New GP. Never spoke with him. I thought if family knows the patient's wishes then there is no need to	
	discuss with the Dr.	
	Proximity- does not live in the same city as mother in law	
	I trust that the family will make the right decsion when the time comes	
	My mother dislikes Dr's - will not talk with Dr, only goes to clinic.	
	Doesn't think Dr would have time to sit down and talk about these types of things.	
	We will deal with it when we go there	
10251037	Why should I talk about it- I have my own opinion	

		PT(site)	PT(all sites)
Domains	Questions	n=0	n=40
Patient Factors	I am not ready to discuss these matters at	-	12.5%(14.3, 0.0,40.0)
	this time with my doctor		
	I have not made the time for it	-	17.5%(33.3, 0.0,60.0)
	I am not comfortable talking about dying	-	2.5%(0.0, 0.0, 25.0)
Family Factors	I trust my parterner, family or surrogate	-	35%(50.0, 8.3, 100)
	decision maker to make the right decision		
	when the time comes		
Doctors Factors		-	17.5%(20.0, 0.0, 50.0)
	decision when the time comes		
	The doctor did not seem interested or	-	2.5%(0.0, 0.0, 14.3)
	have the time for it		
	The doctor didn't ask me	-	45%(25.0, 0.0,83.3)
Process Factors	I have delegated that decision to someone	-	7.5%(12.5, 0.0,50.0)
	else		
	I did not think I had the ability to	-	2.5%(0.0, 0.0, 25.0)
	influence these decisions		

Domains	Questions	FM(site) n=1	FM(all sites) n=26
Patient Factors	This is my relative's decision to make with her/his doctor	-	34.6%(50.0,25.0,54.5)
Family Factors	I am not ready to discuss these matters at this time with her/his doctor	-	11.5%(29.2, 0.0,50.0)
	I have not made the time for it	-	11.5%(29.2, 0.0, 33.3)
Doctors Factors	I trust her/his doctor to make the right decision when the time comes	-	7.7%(12.5, 0.0,33.3)
	The doctor did not seem interested or have the time for it	-	7.7%(12.5, 0.0,33.3)
	The doctor didn't ask me about this	-	46.2%(33.4, 0.0,90.9)
Process Factors	This discussion should be between my relative and her/his doctor	1 (100%)	15.4%(37.5, 9.1, 100)

3c) Reasons for not discussing with patient/family member/surrogate("No" in 3a.vii-viii)

Q3c Verbal Response from the patients

ID	Open text (n=1)
10251013	Made some general comments to brother- all kinds of reasons for not discussing. It's easier when others
	bring it up

Q3c Verbal Response from the FM

ID	Open text (n=2)	
	The patient is an orphan and my family is out of town. we do not communicate often.	
10251021	'Did not look into detail sabout it' Relative (patient) and family will make decisions when the time	
	comes'	

		PT(site)	PT(all sites)
Domains	Questions	n=0	n=2
Patient Factors	I am not ready to discuss these matters at	-	50%(50.0,50.0,50.0)
	this time with my parterner and family		
Family Factors	I trust my partner, family or surrogate	-	50%(50.0,50.0,50.0)
	decision maker to make the right decision		

Domains	Questions	FM(site) n=0	FM(all sites) n=1
Family Factors	I(we) am/are not ready to discuss these matters at this time with my(our) family/relative	-	100%(100, 100, 100)

4. Things make it difficult to talk with doctors/health care professionals prior to hospital about plan of care/use of life-sustaining treatments?

Q4 Verbal Response from the patients

ID	Open text (n=19)
10251005	Just never came up
10251009	They take too long to give me any answers - it is very upsetting- I have been here for 7 days- they have
	not said or done anything - no tests - just waiting.
	Doctors do not have the time to talk to you especially living up North there are not many doctors.
10251011	'It is uncomfortable for me to face facts about the inevitable' I don't feel comfortable talking to the Dr
	about this topic. I am worried that I won't be able to change my mind. I am worried about definitive
	decisions. I was intubated once-it was successful. It is hard to find the write forms.
	Personality- I think drs dont listen. Dont communicate well. Talk down to you. No time to talk.
10251015	My doctor- I don't have faith in her taking care of an older person, she's not interested in my problems.
	Taxonomy- doctors don't ask me about my wishes related to this matter; this issue is not relevant to me at
	this time.
	Wasn't difficult. Taxonomy- doctors don't ask me about my wishes related to this manner.
10251019	
	Never thought of it, I don't care for her
	If I wanted to talk about it I would have. It is not difficult- just don't care. No GP
	Haven't had that many doctors or nurses prior to this admission. Does not come up as a topic unless
	reason for it. In taxonomy section- 'this issue is not relevant at this time', 'doctors don;t ask me about my
	wishes related to this matter'
	Nothing really- not difficult
10251029	They never take more than 3-5 minutes after coming into room. Just basic comments about physical
	health. They don't give me a chance to speak about it.
10251032	Didn't think about it at the time

ID	Open text (n=19)
	Because raised in time when doctors all had special status and you just listened to them, still have that
	kind of respect and don't bring things up. Go to appointments for specific reason. Do not find it difficult
	just did not seem to make a conversation of it.
	My Dr is religious it upsets him so we don't discuss it. Don't want to upset him.
	My family is my doctor
10251043	Doctros can't guarantee you life- never discussed anything that wasn't there to discuss. No reason to
	discuss.
10251044	I don't think anything makes it difficult

Q4 Verbal Response from the FM

	•		
ID	Open text (n=22)		
10251002	Not knowing what the prognosis was and what the available treatments there are		
10251003			
	It was never brought up by Dr. 'natural'		
	'I can't really say. If the doctor is there, we will talk about it.'		
	Nothing really. We are very open - have not thought that it was necessary.		
10251012	'More difficult to understand all the options' 'It is not difficult to talk about. There should be a booklet		
	so that lay people can understand what levels such as 1,2,3,and4 of DNAR mean.'		
	'Angst', feeling of uncertainty, fear of dying, fear of making plan.		
	It is not difficult, we just didn't bring it up		
	physical proximity- does not live in the same city as mother in law		
	If they didn't listen		
	It is not difficult- just did not think about specifics of when to and when not to rescusitate.		
	Has no family Dr.		
10251024	Never have time to go over plans in detail- doctors are too busy and are unavailable to talk to, doctors		
	don't ask me about this matter, doctors focus on other problems during a clinic or office visit like		
	ordering tests and medications		
	The healthcare provider only wanted to talk to our family member about grandmothers condition		
10251027			
	They are in a rush, not thorough, no time to address the patient's concerns.		
	Did not find it difficult- just didn't come up.		
	Not difficult- have to discuss what you have to.		
	10251036 Do not find difficult as long as physician is clear with explanations of plans of care.		
10251037			
	Don't have any problem discussing		
10251043	Nothing- if they ask questions, I try my best to answer questions		

10251043 Nothing- if they ask questions, I	try my best to answer questions

		PT(site)	PT(all sites)
Domains	Questions	n=5	n=90
Patient Factors	Issue not relevant at this time	2 (40.0%)	17.8%(25.0, 0.0, 100)
	My diagnosis and prognosis uncertain	0(0.0%)	6.7%(0.0, 0.0, 50.0)
	I am too sick to talk about this	0(0.0%)	2.2%(0.0, 0.0, 25.0)
Doctors Factors	No GP	0(0.0%)	6.7%(0.0,0.0,14.3)
	I dont know my doctor	1 (20.0%)	12.2%(8.3, 0.0,50.0)
	Doctors are too busy and are unavailable	1 (20.0%)	21.1%(20.0, 0.0, 100)
	to talk to		
	I don't trust my doctor	0(0.0%)	4.4%(0.0,0.0,14.3)
	I don't feel comfortable talking to the	0(0.0%)	6.7%(0.0,0.0,16.7)
	doctor about this topic		
	The Doctor does not seem comfortable	0(0.0%)	1.1%(0.0, 0.0, 5.3)
	talking to me about this topic	. ,	
	Doctors don't ask me about my wishes	1 (20.0%)	23.3%(20.0, 0.0, 100)
	related to this matter	. ,	

Domains	Questions	PT(site) n=5	PT(all sites) n=90
	Doctors focus on other problems during a clinic or office visit like ordering tests and meds	1 (20.0%)	11.1%(8.3, 0.0,25.0)
	Hearing, and or speech, and or language problems make it difficult to communicate with MDs	0(0.0%)	2.2%(0.0, 0.0, 6.7)
Process Factors	Difficult to find information and forms related to ACP	1 (20.0%)	2.2%(14.2, 8.3,20.0)

Questions	FM(site)	FM(all sites) n=64
	11-0	-
	-	20.3%(33.3,22.2,50.0)
	-	17.2%(25.0,11.1,66.7)
My relative does not have a GP	-	6.3%(0.0, 0.0, 22.2)
	-	17.2%(11.1, 0.0, 33.3)
Doctors are too busy and are unavailable	-	15.6%(16.7, 0.0, 100)
to talk to		
I do not trust his/her doctor	-	3.1%(0.0, 0.0, 25.0)
I don't feel comfortable talking to her/his	-	4.7%(0.0,0.0,16.7)
doctor about this topic		
Doctors don't ask me about this matter	-	31.3%(25.0, 0.0,66.7)
Doctors focus on other problems during a	-	6.3%(0.0,0.0,66.7)
clinic or office visit like ordering tests		
and meds		
I/we am/are worried that I/we won't be	-	1.6%(3.4, 0.0, 6.7)
able to change my/our mind/s on a		
decision		
Difficult to find information and forms	-	1.6%(8.4,0.0,16.7)
related to ACP		
	I don't know my relative's doctor Doctors are too busy and are unavailable to talk to I do not trust his/her doctor I don't feel comfortable talking to her/his doctor about this topic Doctors don't ask me about this matter Doctors focus on other problems during a clinic or office visit like ordering tests and meds I/we am/are worried that I/we won't be able to change my/our mind/s on a decision Difficult to find information and forms	Questionsn=0My relative's diagnosis and prognosis uncertain-This issue not relevant at this time-My relative does not have a GP-I don't know my relative's doctor-Doctors are too busy and are unavailable to talk to-I do not trust his/her doctor-I don't feel comfortable talking to her/his doctor about this topic-Doctors don't ask me about this matter-Doctors focus on other problems during a clinic or office visit like ordering tests and meds-I/we am/are worried that I/we won't be able to change my/our mind/s on a decision-Difficult to find information and forms-

5. Things make it easier to talk with doctors/health careprofessionals about same concerns

Q5 Verbal Response from the patients

ID	Open text (n=14)
10251015	If she was more compassionate and interested in what's happening in my age, and if she would listen
	when I ask her to send me to different places. Taxonomy- doctor initiates conversation, for ex, as part of
	annual check-up; doctor has good communication skills.
	nothing- theyre easy to talk to
	Being interested in me
	Just not interested in discussing it with them.
	If the Dr had the time
10251025	When Dr makes suggestions (patient did not outright say this, but continued to talk about liking when
	Drs make suggestions). Taxonomy- doctors have good communication skills, doctor needs honest about
	prognosis, more info about CPR, easier access to info, encourage pts to discuss with their doctors
10251028	I just ask them if I want to bring it up. I feel that I've done it all right, with all investments and living
	wills.
	They are not honest about prognosis. Would help if lawyer was present in conversations
	Just to come out in the open and talk about it, not get mad. Taxonomy- doctor initiates conversation, for
	example, as part of annual check up
10251038	It just makes sense. Would be easier if brought up by Dr but can see how that would be sensitive for
	some people. I would prefer being asked. Taxonomy- doctor initiates conversation, for ex as part of
	annual check up

ID	

Open text (n=14)

10251040 No problems- if I have a health problem I would talk about it, but don't visit often.

10251041 Nothing- I don't want to talk to the doctor

10251042 If I knew my Dr better- I've only seen him a couple of times

10251043 Nothing makes it easier- if asked, I would explain thinkgs- if I wasn't living the ilfe I expected, I wouldn't want to finish it.

Q5 Verbal Response from the FM

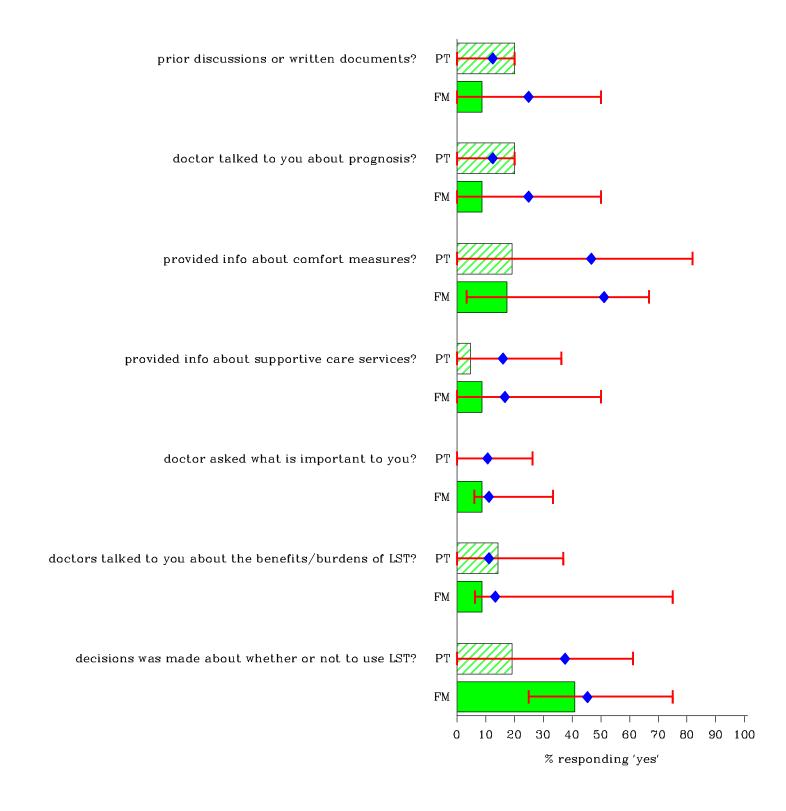
	-
ID	Open text (n=15)
10251002	If I had more information so that I could prepare and discuss it. Once I have answers to my questions I
	am quite willing to talk about it. I want to know my choices first.
10251006	'She is quite happy with the nurses - we don't see the doctor- he comes in the middle of the week.'
10251008	If doctors brought it up Taxonomy resonse: Doctors initiates conversation, for example, as part of
	annual check-up.
10251012	'It would be better to schedule an appointment so family can all be there and also give some reading
	material in advance so that they can make informed decisions.'
10251014	Our daughters father-in-law died. We were aware of the living will that he had then seeing the
	commercial on tv made us talk about it, wanted to make plans to make it easier for our daughter to
	discuss with health care members.
	closer proximity
	Make an appointment ahead of time
	Did not look into detail about it. Relative and family will make decision when time comes
	If Dr doesn't bring it up, obviously don't want to as not sure how knowledgeable Dr is about these things.
	She is ready and willing to plan ahead as the widow
10251033	If doctor seemed patient and spent the time, and showed they were addressing patient's concerns
	specifically. Haven't seen GP since admission.
	We do not hesitate to ask questions, but I have to ask questions for wife.
10251035	Depends on attitude of Dr- needs to be honest. Told pt recently that he was totally healthy and now he
	needs valve replacement. All taxonomy checkboxes ticked off as well except 'other team members such
	as nurses would be easier to talk to about this than physicians'.
10251036	If chance to meet with Dr, did not seem to find difficult

10251037 I have no problem talking about it.

Domains	Questions	PT(site) n=10	PT(all sites) n=151
Doctors Factors	Doctor initiates conversation, for	7 (70.0%)	72.8%(75.5, 0.0, 100)
	example, as part of annual check-up		
	Doctor has good communication skills:	1 (10.0%)	15.9%(9.6, 0.0,50.0)
	listening, convey personal interest,		
	compassion		
	Doctor to be honest about prognosis	2 (20.0%)	2.6%(0.0,0.0,20.0)
Process Factors	More information available about CPR,	5 (50.0%)	15.9%(16.7, 0.0,50.0)
	palliative care, and other end of life		
	treatment options before patients too ill		
	Easier access to information about this,	0(0.0%)	2%(0.0, 0.0, 16.7)
	for example, on-line information		
	Family of patients included in	1 (10.0%)	13.9%(12.5, 0.0, 50.0)
	conversations related to ACP		
	Encourage patients who wish to discuss	1 (10.0%)	8.6%(4.3, 0.0, 45.5)
	this tell doctors their wishes		
	Other team members such as nurses	0(0.0%)	3.3%(0.0, 0.0, 50.0)
	would be easier to talk to about this than		
	physicians		

Domains	Questions	FM(site) n=8	FM(all sites) n=110
Doctors Factors	Doctor initiates conversation, for example, as part of annual check-up	7 (87.5%)	71.8%(74.6, 0.0, 100)
	Doctor has good communication skills: listening, conver personal interest, compassion	1 (12.5%)	15.5%(16.3, 0.0,50.0)
Process Factors	Doctor to be honest about prognosis More information available about CPR, palliative care, and other end of life treatment options before patients too ill	0 (0.0%) 5 (62.5%)	4.5%(0.0, 0.0,25.0) 25.5%(25.0, 0.0,62.5)
	Easier access to information about this, for example, on-line information	1 (12.5%)	5.5%(0.0, 0.0, 25.0)
	Include family of patients in conversations related to ACP	1 (12.5%)	26.4%(25.0, 0.0, 55.6)
	Encourage patients who wish to discuss this and convey their wishes	0(0.0%)	5.5%(0.0, 0.0,42.9)
	Other team members such as nurses would be easier to talk to about this than physicians	0(0.0%)	1.8%(0.0, 0.0,25.0)

Were you asked about...



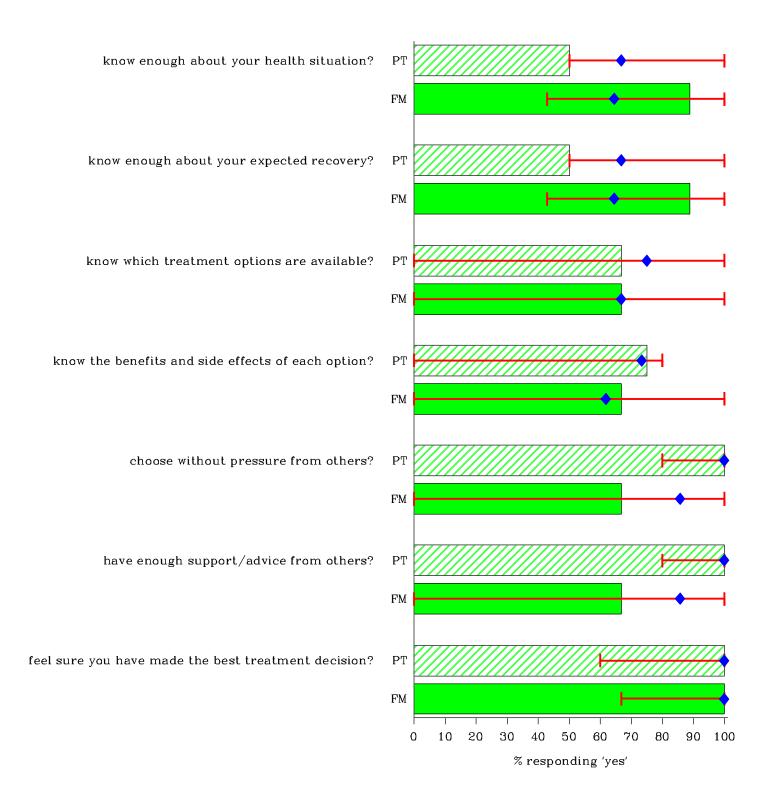
8. Who was present during the discussion with the doctor about the use of life sustaining medical treatments?

RESPONSES	PT(site) n=3	PT(all sites) n=63	FM(site) n=7	FM(all sites) n=86
Spouse	33.3%	28.6%(25.0, 0.0, 100)	14.3%	43%(43.4, 0.0,71.4)
Surrogate	66.7%	23.8%(20.0, 0.0,66.7)	28.6%	16.3%(7.7, 0.0, 100)
Other family	33.3%	41.3%(50.0, 0.0, 100)	71.4%	48.8% (52.3, 0.0, 100)
Other	0%	20.6%(10.0, 0.0, 100)	14.3%	11.6%(3.9, 0.0, 33.3)

9. What is your understanding of the decision?

RESPONSES	PT(site) n=4	PT(all sites) n=109	FM(site) n=9	FM(all sites) n=97
	0%	-	0%	-
Unsure	75%	4.6%(0.0, 0.0, 75.0)	0%	3.1%(0.0, 0.0, 9.1)
Declined	0%	1.8%(0.0,0.0,10.0)	0%	3.1%(0.0, 0.0, 33.3)
Aggressive use of heroic measures and	0%	16.5%(0.0, 0.0, 50.0)	11.1%	18.6%(10.1, 0.0,60.0)
artificial life sustaining treatments including CPR to keep me alive at all costs				
Full medical care but in the event my heart stops, or my breathing stops, no CPR	25%	19.3%(20.0, 0.0,50.0)	33.3%	17.5%(17.9, 0.0,66.7)
Doctors will be focused on my comofrt and alleviate suffering and not on being kept alive by artificial means or heroic measures	0%	27.5%(27.3, 0.0,83.3)	33.3%	35.1%(34.8, 5.9,71.4)
A mix of above (e.g. try to fix problems but if not getting better switch to focusing only on my comfort even if it hastens death)	0%	30.3%(16.7, 0.0,57.9)	22.2%	22.7%(23.6, 0.0,50.0)

Do you...



11. Was there anything we could have done differently to improve the process of making a decision about medical treatments to sustain life in the event your (relative's) condition deteriorated?(open ended question)

Responses from patients

ID	Open text (n=4)
10251016	No, did well
10251021	
10251038	No- doctors should know when to quit carving on a person, to understand what they are capable of doing.
	Don't put me down just because I'm blind- keep going if there is a chance of improving someones life. I
	believe system in BC is terribly abused, There should be more options in preventative medicine.
10251042	I can't say because I can't remember.

Responses from FM

ID	Open text (n=9)
	no answer
	'It would be better to have something in writing so you know what was discussed and decided and also to
	have something to understand and explain all treatment options i.e. afraid that if you make a decision of
	no life support you won't fix a fixable problem i.e. if needs a chest tube for a collapsed lung.'
10251016	Thinks they have been very fair. Think it should be part of family doctor's physical- never at level of
	hospital
10251017	no
10251018	No
10251024	Thinks fifth day to talk about ACP is the right day- sometimes its too early to make these decisions.
	Thinks Drs try to pull the plug a little too early sometimes. Want treatment to go a little longer.
	pretty clear cut, nothing to add.
	Could use an update but otherwise have conducted many tests but haven't spoken to Dr since ER.
10251043	Nothing else- we know he has a lot of problems. It's in God's hands.

13. In general, what kinds of things make it difficult to talk with doctors/health care professionals in hospital about plan of care/use of life-sustaining treatments?

Section 4 Q13 Verbal Response from patients

ID	Open text (n=17)
	Drs are always in such a rush - so busy - there time is so limited - you don't really think about it.
10251011	'I don't feel that there are limitations - I do not feel challenged. I value the candour - the opportunity has not arouse so far during this admission. The Drs are very busy to talk.'
10251015	Have not had a chance to talk with them yet. I think you should have an appointment to discuss these
	issues. Taxonomy- doctors don't ask me about my wishes related to this matter.
10251016	not difficult
10251019	I am too sick and tired
	I haven't sen any doctors.
	It is not difficult!
	I have never seen a docotr since I was admitted.
10251028	I haven't spoken to Drs that I wanted to speak to. Not sure how busy they are, just has never come up yet.
	Taxonomy: Drs dont ask me about my wishes, this issue is not relevant, focused on the problem during
	clinic visits.
10251029	They don't have time to listen- don't give me time. If they start takling about it, they say 'I have to go to
	another pt'. Makes it very difficult and unpleasant.
	Don't talk to or know doctors.
10251038	Not difficult- doctors are very amiable and will carry on a medical conversation which helps.

ID	Open text (n=17)
10251040	Does not bother me at all- have already made up my mind so if it comes along, I'll let them know.
10251041	Nobody asks
10251042	The occasion didn't come up.
10251043	not difficult
10251044	I have had no reason to bring it up. Taxonomy- my diagnosis and prognosis are uncertain

Section 4 Q13 Verbal Response from FM

ID	Open text (n=18)
10251002	It is not difficult
10251004	Doctors have not brought up the matter. Doctors have not discussed any care plan with the family yet. Taxonomy- my relative's diagnosis and prognosis is unclear or uncertain, doctors ond ask me about my wishes, difficult to find info and forms related to ACP.
10251006	'I don't think there are any problems if you understand it. If you don't then maybe there will be a situation.
10251008	'To talk in private - family should be asked to step away from mom and be asked questions privately' Taxonomy responses: Doctors are too busy and are unavailable to talk to Doctors don't ask me about my wishes related to this matter Doctors focus on other problems during a clinic or office visit like ordering tests and medications
10251012	As above
10251014	If Drs bring it up or other health care members bring it up we are quite happy to talk about it.
10251016	Don't find it difficult
10251017	nothing makes it difficult
10251018	Not having the time
10251021	It is not difficult- do not want to feel rushed. Very important to feel relaxed about the discussions.
10251022	Communication with Drs not being available- patient advocate and relatives involved in decisions.
10251024	Not difficult, except that they need to have time to talk about it.
	Its very easy
	If they're around it would be easier. Dr to follow up on family and patient's decisions regarding life sustaining treatments.
	Not difficult- never came up
10251035	Nothing. Taxonomy: Drs are too busy and are unavailable to talk to
10251039	Not difficult
10251043	Not really difficult, it's part of life

10251043 Not really difficult- it's part of life

		PT(site)	PT(all sites)
Domains	Questions	n=4	n=91
Patient Factors	My diagnosis and prognosis unclear or	1 (25.0%)	28.6%(21.6, 0.0, 100)
	uncertain		
	I am too sick to talk about this	0(0.0%)	2.2%(0.0, 0.0, 18.2)
	Issue not relevant to me at this time	1 (25.0%)	7.7%(0.0,0.0,45.5)
Doctors Factors	I dont know my doctor and he/she does	1 (25.0%)	16.5%(10.8, 0.0,61.5)
	not know me		
	Doctors have no time or are unavailable	0(0.0%)	35.2%(30.3, 0.0,75.0)
	to talk		
	I dont trust my doctor	0(0.0%)	2.2%(0.0, 0.0, 12.5)
	I dont feel comfortable talking to the	0(0.0%)	9.9% (2.5, 0.0, 50.0)
	doctor about this topic		
	The doctor does not seem comfortable	0(0.0%)	1.1%(0.0, 0.0, 9.1)
	talking to me about this topic	. ,	
	Doctors dont ask me about my wishes	0(0.0%)	15.4%(7.1,0.0,100)
	related to this matter	. ,	
	Doctor doesnt care about me, not	1 (25.0%)	2.2%(0.0, 0.0, 33.3)
	compassionate	` '	

Domains	Questions	PT(site) n=4	PT(all sites) n=91
	Hearing, and or speech, and or language problems make it difficult to communicate with MDs	1 (25.0%)	1.1%(0.0, 0.0,25.0)
Process Factors	I am worried that I wont be able to change my mind on a decision	1 (25.0%)	4.4%(0.0, 0.0,50.0)
	Emergency room is too busy and stressful to talk about this	0(0.0%)	24.2%(18.2, 0.0,55.0)
	No opportunity to discuss this with family present	0(0.0%)	6.6%(5.0, 0.0,25.0)
	Difficult to find information and forms related to ACP	1 (25.0%)	2.2%(0.0, 0.0,25.0)

		FM(site)	FM(all sites)
Domains	Questions	n=2	n=69
Patient Factors	My relatives diagnosis and prognosis is	-	37.7%(41.7,20.0,66.7)
	unclear or uncertain		
	My relative is too sick to talk about this	-	1.4%(0.0, 0.0,11.1)
Family Factors	I dont feel comfortable talking to the	-	5.8%(0.0, 0.0, 22.2)
	Doctor about this topic		
	This issue not relevant to me/us at this	-	11.6%(11.1, 0.0,80.0)
	time		
Doctors Factors	I dont know who my relatives doctor is	0(0.0%)	18.8%(11.1, 0.0,44.4)
	Doctors dont ask me about my wishes	1 (50.0%)	24.6%(25.0, 0.0, 100)
	related to this matter		
	Doctors are too busy and are unavailable	1 (50.0%)	27.5%(14.3, 0.0,50.0)
	to talk to		
	Hearing, and or speech, and or language	0(0.0%)	1.4%(0.0, 0.0,10.0)
	problems make it difficult to		
	communicate with doctors		
	Doctors focus on other problems during a	0(0.0%)	1.4%(0.0, 0.0,20.0)
	clinic or office visit like ordering tests		
	and meds		
Process Factors	No opportunity to discuss this with	-	13%(11.1, 0.0,60.0)
	family present		
	Difficult to find information and forms	-	7.2%(8.4, 0.0, 100)
	related to ACP		
	I am worried that I wont be able to	-	1.4%(0.0, 0.0,11.1)
	change my mind on a decision		
	Emergency room is too busy, and	-	21.7%(0.0, 0.0,50.0)
	stressful to talk about this		

14. What kinds of things make it easier to talk with doctors/health care professionals about same concerns in hospital?

ID	Open text (n=10)
10251011	These are not my usual Drs. I am not going to see them again - If there was someone who I was familiar
	with or had the potential to be familiar with I would discuss these matters.'
10251019	Acceptance of what I have to say
10251020	I would like a direct answer, the true story.
10251021	If they don't want to talk about it, I don't either.

ID	Open text (n=10)
	Mostly my decision- Taxonomy: one family meeting is enough. Doctor initiates conversation, good
	communication, honest about prognosis, more info available, easier access to info, encourage patients to
	discuss wishes, schedule family meeting, have conversation when pt stabilized.
	Just that they don't bring it up
	When describing the surgery, they should tell you the risks and if they encounter one or more of risks,
	ask what patient's decision would be.
	I like a Dr I can talk to that will listen to another person's views, that will talk to me with good bedside
	manner, some don't feel comfortable talking about it.
	I'm not thinking about it.
10251043	If they bring it up.

Section 4 Q14 Verbal Response from FM

ID	Open text (n=10)
10251012	As above
	If health care team brings it up. We rely on the services and advice of healthcare team.
10251017	they have been great. Taxonomy- doctors initiate conversation; doctor has good communication skills'
	doctor is honest about prognosis
10251018	Making the time. Taxonomy: doctor has good communication skills- listening, convey personal interest,
	compassion; doctor to be honest about prognosis
10251022	Patient advocate and relatives involved in decisions.
10251024	By the time you wait to discuss with patient, might be too late- now she is semi-conscious.
	Easy- caring staff is very caring, that makes it easy to approach team.
	They bring it up and listen to our concerns
10251034	No trouble talking to them or asking questions
10251035	Haven't talked to any except surgeon on phone

10251035 Haven't talked to any except surgeon on phone

Domains	Questions	PT(site) n=11	PT(all sites) n=151
Family Factors	Include family of patients in conversations related to ACP	4 (36.4%)	33.8%(36.4,16.7, 100)
Doctors Factors	Doctor initiates conversation	8 (72.7%)	70.2%(75.0,33.3,100)
	Doctors has good communication skills Doctor is honest about prognosis	2 (18.2%) 1 (9.1%)	14.6%(18.4, 0.0,33.3) 5.3%(0.0, 0.0,12.5)
Process Factors	More available info Easier access to info	5 (45.5%) 0 (0.0%)	19.2%(25.0, 0.0, 100) 0.7%(0.0, 0.0, 3.7)
	Have this conversation when patients are stabilized and not in crisis	1 (9.1%)	6.6%(0.0, 0.0,17.4)
	Encourage patients who wish to discuss this and convey their wishes	1 (9.1%)	9.3%(0.0, 0.0,58.3)
	Other team memebers(ie.Nurses) would be easier to talk to about this	0(0.0%)	2.6%(0.0,0.0,33.3)
	Scheduel family meeting to discuss this issue	1 (9.1%)	4.6%(0.0, 0.0, 16.7)

Domains	Questions	FM(site) n=10	FM(all sites) n=102
Doctors Factors	Doctor initiates conversation	9 (90.0%)	74.5%(73.8,25.0, 100)
	Doctor has good communication skills: listening, convey personal interest, compassion	1 (10.0%)	11.8%(9.2, 0.0,50.0)
	Doctor to be honest about prognosis	0(0.0%)	5.9%(0.0, 0.0,25.0)
Process Factors	Include family of patients in these conversations	7 (70.0%)	61.8%(66.7, 0.0, 100)

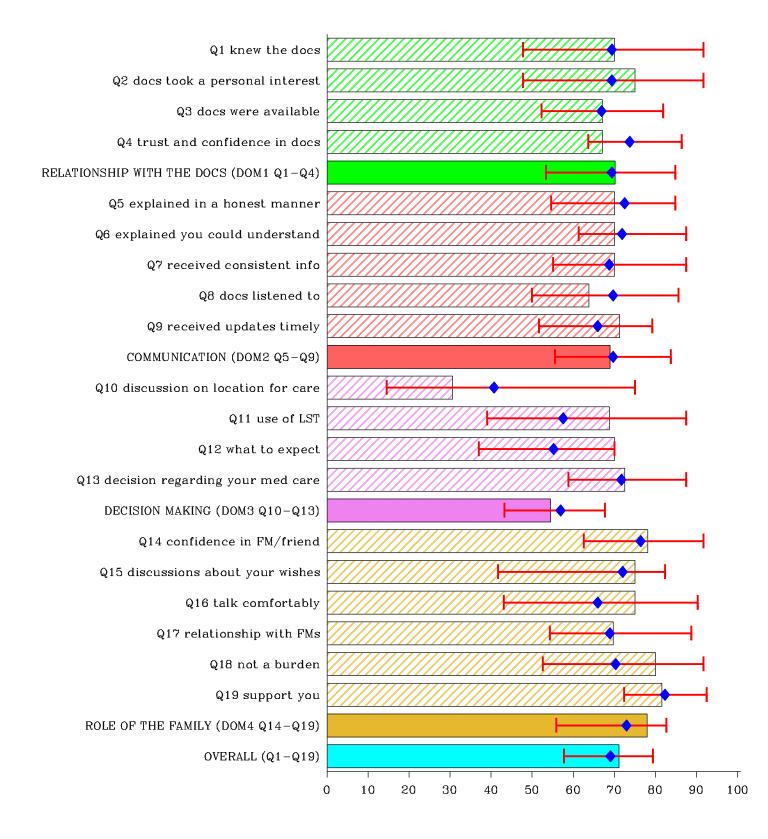
Domains	Questions	FM(site) n=10	FM(all sites) n=102
	Encourage patients who wish to discuss this and convey their wishes	1 (10.0%)	3.9%(0.0, 0.0,14.3)
	Other team members such as nurses would be easier to talk to about this than physicians	0(0.0%)	2.9%(0.0, 0.0,50.0)
	More information available about CPR, palliative care, and other end of life treatment options before a patient is too ill	0(0.0%)	2%(0.0, 0.0, 8.3)
	Schedule family meeting to discuss this issue	0(0.0%)	10.8%(2.4, 0.0,42.9)
	Easier access to information about this,(For example, on-line information	0(0.0%)	1%(0.0, 0.0,25.0)

SECTION 5: CANHELP

Patient Version

Hatched bars represent individual questions and solid bars represent domain scores or overall scores. Different colors were used for questions in different domains.

You are satisfied that ...

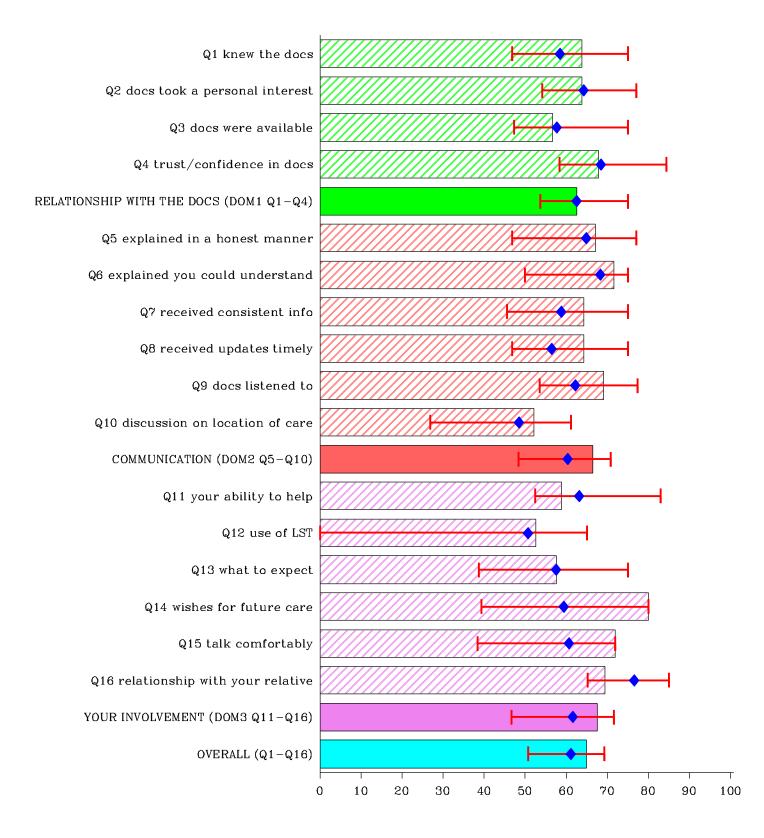


SECTION 5: CANHELP

Family Member Version

Hatched bars represent individual questions and solid bars represent domain scores or overall scores. Different colors were used for questions in different domains.

You are satisfied that ...



SECTION 6: Documentation of Advance Care Plans/Advance Directives in the Hospital Chart at the end of the interview

a) Does the hospital use a green or blue sleeve or any other strategy to easily localize ACP/AD tools in the medical record?

RESPONSES	Your site(n=23)	All sites(n=227)
Yes	100%	72.2%(100,0,100)

b) Was a green or blue sleeve (or other tool) on the chart on the day of enrollment

RESPONSES	Your site(n=23)	All sites(n=163)
Yes	65.2%	60.1%(64.8,0,100)

c) if Yes, what was in the green/blue sleeve/other tool?

RESPONSES	Your site(n=21)	All sites(n=137)
Goals of care designation or MOST form	0%	21.9%(0,0,100)
Options for care order	100%	62.8%(90,0,100)
ACP tracking record	0%	7.3%(0,0,100)
Representation agreement or personal	0%	4.4%(0,0,35.7)
directive		
Advance directive or living will	0%	3.6%(0,0,40)
Levels of intervention form	4.8%	0.7%(0,0,4.8)
My voice work book	0%	0.7%(0,0,7.1)
Other (specify)	4.8%	15.3%(0,0,66.7)

Is there documentation of a discussion recorded on the tracking record?

RESPONSES	Your site(n=0)	All sites(n=1)
Yes	-	100%(100,100,100)

2a)Is there any other advance directive, living will, goals of care designation or other end of life care planning tools present on the chart or electronic record?

RESPONSES	Your site(n=0)	All sites(n=172)
Goals of care designation or MOST form	-	55.8%(0,0,100)
Options for care order	-	27.9%(0,0,88.2)
ACP tracking record	-	0.6%(0,0,2.8)
Representation agreement or personal	_	1.2%(0,0,5.6)
directive		
Advance directive or living will	-	7%(2.7,0,100)
Levels of intervention form	-	2.3%(0,0,25)
Other (specify)	-	25.6%(19.8,0,100)

3) Evidence in the chart that some member of the health care team attempted to reach a community care worker about this patients prior expressed wishes

RESPONSES	Your site(n=44)	All sites(n=409)
Yes	2.3%	5.9%(2.6,0,39.4)

Disseminating the Results of Your Site Report

Your site has committed a significant amount of time to participate in the ACCEPT Study. We have committed a significant amount of time and resources to produce these site reports. We encourage you to use your site report as a unique opportunity to highlight patient and relative involvement, perceived barriers/facilitators and satisfaction with communication and decision-making regarding Advance Care Planning, and inform quality improvement initiatives.

The following are a few suggestions of useful forums from which to disseminate the site reports:

- Print off and copy the site report and distribute to key stakeholders.
- Lead a small group interactive workshop with local doctors and nurses to strategize on ways to meet the expectations and respect the wishes of patients and/or family.
- Produce and post a poster outlining your main strengths and weaknesses and suggested changes.
- Meet with relevant management and/or Hospital administration to discuss barriers and strategies to improve.

For additional resources to help with your quality improvement activities, see www.advancecareplanning.ca Thank you for your support with the ACCEPT Study. The next opportunity to participate in this initiative will be in end of 2012 or early 2013.(check www.advancecareplanning.ca for details).

If you have any suggestions on making this report more useable, or have any questions please contact Dr. Daren Heyland (dkh2@queensu.ca), Janet Overvelde (Project Leader – overvelj@kgh.kari.net). We would welcome your feedback. We look forward to working with you again.