



## Advance Care Planning

for

Advance Care Planning Collaborative Research and Innovation  
Opportunities Program

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### Alberta Public Opinion Study – Fall 2013

October 2013

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# Advance Care Planning – Awareness and Preparation

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## Methodology


-  **Population** The province of Alberta has a total population of 4,025,074 residents (Statistics Canada, July 1, 2013) approximately 77% of which are 18 years of age or older for an adult population of approximately 3,010,000.
-  **Sample** Data were collected by Lethbridge College and Athabasca University students enrolled in STS2270 – Social Science Research Methods and PSC1150 – Local Government in the fall of 2013. Students interviewed 987 adult Alberta residents by telephone from October 5 to 6, 2013 under the supervision of Canadian Studies faculty members Faron Ellis PhD and Marda Schindeler MA. Telephone numbers were selected from a sample drawn from InfoGroup directories. We sincerely thank all participants who took time out of their day to respond to our inquiries. Further results from this study and results from past studies can be accessed by visiting the CSRL web pages at: [www.lethbridgecollege.ca/go/csrl](http://www.lethbridgecollege.ca/go/csrl)
-  **Representativeness** Analysis of the demographic data indicates that, within acceptable limits, the sample accurately represents the demographic distribution of the adult population within the province of Alberta. The sample has been statistically weighted where necessary to even better reflect the demographic distribution of the population (gender and age).
-  **Confidence** The weighted sample yields a margin of error of  $\pm 3.1$  percentage points, 19 times out of 20. The margin of error increases when analyzing sub-samples of the data (Calgary  $\pm 5.4$  percentage points, Edmonton and immediate area  $\pm 5.6$  percentage points, North  $\pm 7.6$  percentage points, South  $\pm 7.2$  percentage points, 19 times out of 20).
-  **IB Commons Call Centre** Students conducted interviews using the facilities of the Lethbridge College IB Commons Call Centre and applications originally developed by the Open Source Learning Lab (OSLL). We thank James Manis PhD and OSLL for their efforts in working with us to establish the IB Commons Call Centre. We also thank members of Lethbridge College's IT team who have assumed a number of maintenance and support duties over the years.
-  **Sponsorship** These data are part of a larger study of the opinions and attitudes of Alberta residents conducted by the Citizen Society Research Lab at Lethbridge College. This particular set of questions was sponsored by the advance care planning Collaborative Research and Innovation Opportunities program Funded by Alberta Innovates Health Solutions. We thank CRIO for their support of our research endeavors.

## Advance Care Planning – Albertans' Awareness and Preparation

 **Introduction:** This report analyzes Albertans' opinions concerning seven advance care planning awareness and preparation items. Levels of awareness and preparation are relatively low and where differences between sub-groups exist, they are mostly based on anticipated differences between age groups, education levels, and gender differences.

 **Seven advance care planning awareness-preparation items:** Awareness and preparedness was measured by asking respondents if they had ever heard of advance care planning (ACP), initially without defining ACP and then with a definition; if they had ever discussed ACP with family or with a healthcare professional; if they have a written ACP; if they have a personal directive; and if they had ever heard the term goals of care designations. Respondents were also asked to rate their personal health using a scale that ranged from zero (worst imaginable health) to 100 (best imaginable health).

- Only approximately one-quarter of Albertans (25.9%) had heard the term advance care planning when asked without being provided with a definition of the term.
- Once they were provided a definition and the term was likened to a “living will,” four out of every five Albertans (80.3%) stated that they were familiar with the term.
- A majority of Albertans (57.0%) have discussed their own advance care planning with a family member or close friend.
- However, very few (16.5%) have also had those discussions with a healthcare professional.
- Nearly one-third of Albertans (32.1%) have a written advance care plan.
- Almost two of every five Albertans (39.4%) have a written personal directive.
- Very few Albertans (11.1%) have ever heard the medical term “goals of care designations.”

 **Index and detailed tabular data:** A brief summary of a cumulative index of ACP awareness and preparation is presented below along with tabular data detailing the item-specific results. Individuals interested in further information can contact the authors of this study directly or contact Dr. Jessica Simon, Scientific Office, Care Planning Collaborative Research and Innovation Opportunities Program, Room 3E44, TRW Building, 380 Hospital Drive, N.W. Calgary, AB T2N 4Z6.

## Albertans' Self-evaluations of Personal Health (%)

When asked to evaluate their own health by using a scale that ranges from zero, worst imaginable health, to 100, best imaginable health, Albertans indicated they believe they are in good health. Fewer than one in twenty rates their health as 40 or lower, only one in ten rates their health as less than 50, the midpoint of the scale. Nearly four out of every five rate their health as 70 or better, with the Alberta mean (79.4) and median (80.8) falling clearly on the healthier side of the continuum. In fact, two of every five Albertans rate their health as 90 or better.

No significant regional differences are measured when Albertans self-evaluate their current state of health.

### Health Self-evaluations by Region of Alberta

	Calgary	Edmonton	North	South	Alberta
Mean	79.3	79.7	77.9	80.6	79.4
Median	83.7	80.0	80.0	80.6	80.0
Std. Dev.	18.6	18.1	17.1	16.5	17.8

Range = 0 (worst health) to 100 (best health)

## Seven Advance Care Planning Awareness-Preparation Items (%)

When queried about advance care planning, approximately one-quarter of Albertans are familiar with the term. When ACP is associated with 'living wills' four out of every five Albertans recognize the term. A majority has discussed ACP with family, but only 16.5% have discussed the issue with a healthcare professional. Nearly one-third have a written ACP, while slightly more have a written personal directive. Very few Albertans are familiar with the term 'goals of care designation.'

No significant regional differences were measured on any of the items.

### ACP Awareness and Preparation by Region of Alberta (% yes)

	Heard of ACP	Heard of ACP (probe)	Discussed ACP with Family	Discussed ACP with HCP	Have Written ACP	Have Personal Directive	Heard of GCD
All Alberta	25.9	80.3	57.0	16.5	32.1	39.4	11.1
North	21.6	85.8	60.1	17.5	39.0	48.4	7.9
Edmonton	27.7	76.1	59.5	16.5	29.9	38.6	12.2
Calgary	26.1	82.0	55.5	17.9	33.6	38.4	10.0
South	26.6	79.8	53.3	13.2	26.9	34.8	13.3

## Advance Care Planning Awareness-Preparation Index (2013) (means)



### Index of Advance Care Planning Awareness-Preparation:

An index of ACP awareness was created by summing the affirmative responses to the seven questions thereby allowing for easier regional and demographic comparisons. The index scores range from a possible “0.0” for the least aware- prepared Albertans, to “7.0” for the most aware-prepared. The mean score for the province as a whole is 2.6, clearly less aware-prepared than the midpoint of the range (3.5).



As was partially indicated above, few regional differences on the items are measured. When combined, some minor differences emerge with northern Albertans most aware-prepared, followed by Calgarians and Edmontonians. Southern Albertans are the least aware-prepared but these slight aggregate regional differences are not statistically significant.



Gender has a significant impact on awareness-preparedness with women more aware-prepared than men. Education impacts awareness in that as education levels rise, so too does awareness-preparedness. Similarly, as age increases so too does awareness-preparedness. Income does not significantly impact awareness-preparedness, although middle income households are slightly more aware-prepared than are upper-income and lower-income resident. Amount of religious participation has no impact on awareness-preparation.



For those interested in further explanation concerning the construction of the index or for a more extensive analysis, please contact the authors of the study.

### Advance Care Planning Awareness-Preparation Index (mean scores)

Region	<u>North</u>	<u>Edmonton</u>	<u>Calgary</u>	<u>South</u>	<u>All Residents</u>
	2.8	2.5	2.6	2.4	2.6
Gender*	<u>Male</u>	<u>Female</u>			
	2.4	2.8			
Income	<u>Under \$60,000</u>	<u>\$60-\$120,000</u>	<u>Over \$120,000</u>		
	2.4	2.7	2.6		
Religious Participation	<u>1-3 per month/more</u>	<u>Several per year</u>	<u>Rarely/never</u>		
	2.6	2.6	2.6		
Education*	<u>High School or Less</u>	<u>Some Post-secondary</u>	<u>College-Tech-Trade</u>	<u>University Grad</u>	
	2.3	2.5	2.6	2.8	
Age*	<u>18-29</u>	<u>30-44</u>	<u>45-64</u>	<u>65 and older</u>	
	1.9	2.3	2.8	3.2	

\* sig < 0.05

Range = 0 (uninformed-prepared) to 7 (informed-prepared)

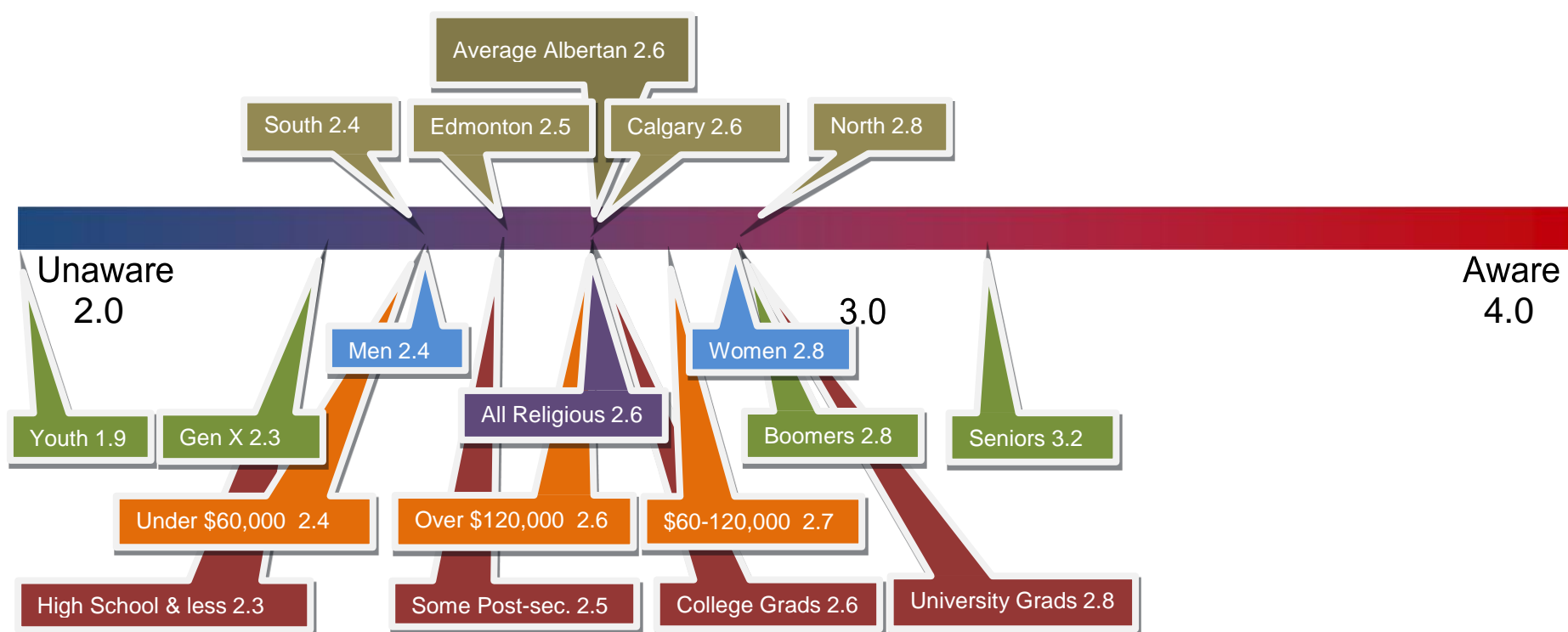
## Advance Care Planning Awareness-Preparation Index (2013) (means)



This graphical presentation below is based on the tabular data that appears on the previous page and demonstrates where various groups of Albertans place themselves on the awareness-preparation continuum.

The graph is organized with the provincial average (mean) and the regional averages above the bar while various demographic groups are found below the bar.

Typical patterns of opinion divergence are measured between demographic sub-groups. For example, as expected, older, better educated, and female Albertans are more prepared-aware than are other groups.



## Health Thermometer by Demographic Group (2013)(%)

- When asked to rate their own health using a scale that ranges from zero, worst imaginable health, to 100, best imaginable health, Albertans believe that they are in good health.
- No statistically significant differences in personal health self-evaluations are measured between the different regions of the province or between various demographic groups. In fact, the results are remarkable for their consistency across all demographic/regional categories.

Region of Province	Calgary	Edmonton	North	South	All Alberta
Mean	79.3	79.7	77.9	80.6	79.4
Median	83.7	80.0	80.0	80.6	80.0
Std. Dev.	18.6	18.1	17.1	16.5	17.8

Gender	Male	Female	All Albertans
Mean	79.6	79.2	79.4
Median	80.0	80.0	80.0
Std. Dev.	18.1	17.5	17.8

Household Income	Under \$60,000	\$60,000 to \$120,000	Over \$120,000
Mean	78.3	79.7	81.6
Median	80.0	80.0	85.0
Std. Dev.	19.7	15.8	16.2

Religious Participation	2-3 times/month-more	Several times/year	Rarely-never
Mean	78.8	76.7	79.9
Median	80.0	80.0	80.0
Std. Dev.	17.0	19.1	18.0

Education	High School or less	Some Post-secondary	College-Tech-Trade	University Grad
Mean	77.0	77.6	78.2	82.5
Median	80.0	80.0	80.0	88.3
Std. Dev.	18.6	19.9	18.0	15.7

Age	18-29	30-44	45-64	65 and older
Mean	82.5	80.6	78.9	76.0
Median	89.0	85.0	80.0	80.0
Std. Dev.	18.2	16.2	17.4	19.1

Notes: Due to rounding, proportions may not total exactly 100%; \* sig < 0.05



## Heard of Advance Care Plan by Demographic Group (2013) (%)

- When not provided with a definition, only slightly more than one-quarter of all Albertans (25.9%) recall having heard the term advance care planning (ACP).
- No significant regional variations are evident although northern Albertans outside of Edmonton (21.6%) are slightly less familiar with the term than are other Albertans.
- Age is the only demographic variable that significantly impacts awareness of the term ACP with seniors (37.2%) indicating greater levels of awareness than other age groups, particularly Gen Xers (18.4%).

Region of Province	Calgary	Edmonton	North	South	All Alberta
Yes	26.1	27.7	21.6	26.6	25.9
No	73.9	72.3	78.4	73.4	74.1

Gender	Male	Female	All Albertans
Yes	24.5	27.4	25.9
No	75.5	72.6	74.1

Household Income	Under \$60,000	\$60,000 to \$120,000	Over \$120,000
Yes	26.9	25.4	25.6
No	73.1	74.6	74.4

Religious Participation	2-3 times/month-more	Several times/year	Rarely-never
Yes	26.1	28.2	24.9
No	73.9	71.8	75.1

Education	High School or less	Some Post-secondary	College-Tech-Trade	University Grad
Yes	24.6	26.1	23.5	29.0
No	75.4	73.9	76.5	71.0

Age*	18-29	30-44	45-64	65 and older
Yes	25.7	18.4	24.3	37.2
No	74.3	81.6	75.7	62.8

Notes: Due to rounding, proportions may not total exactly 100%; \* sig < 0.05

## Heard of Advance Care Plan by Demographic Group (2013) (%) – Probe with Definition

- When provided with a definition that likened advance care plans to 'living wills', approximately four out of every five Albertans (80.3%) indicated they were familiar with the term ACP.
- No significant regional variations are evident although northern Albertans outside of Edmonton (85.8%) are slightly more familiar with the term than are other Albertans.
- Age, gender and education impact awareness of the defined term ACP with Boomers and seniors more aware than are Gen Xers and the youth. Women (85.6%) are slightly more familiar than are men (75.3%), while university and college graduates are more familiar with the term ACP than are those without a post-secondary credential.

Region of Province	Calgary	Edmonton	North	South	All Alberta
Yes	82.0	76.1	85.8	79.8	80.3
No	18.0	23.9	14.2	20.2	19.7

Gender*	Male	Female	All Albertans
Yes	75.3	85.6	80.3
No	24.7	14.4	19.7

Household Income	Under \$60,000	\$60,000 to \$120,000	Over \$120,000
Yes	78.1	84.4	83.3
No	21.9	15.6	16.7

Religious Participation	2-3 times/month-more	Several times/year	Rarely-never
Yes	83.3	79.2	81.2
No	16.7	20.8	18.8

Education*	High School or less	Some Post-secondary	College-Tech-Trade	University Grad
Yes	71.6	78.7	83.3	86.4
No	28.4	21.3	16.7	13.6

Age*	18-29	30-44	45-64	65 and older
Yes	62.5	78.0	90.0	84.5
No	37.5	22.0	10.0	15.5

Notes: Due to rounding, proportions may not total exactly 100%; \* sig < 0.05

## Discussed Advance Care Planning with Family by Demographic Group (2013)(%)

- A clear majority of Albertans (57.0%) have discussed their advance care plans with family members or a close friend.
- No significant regional variations are evident although Edmontonians and other northern Albertans are slightly more likely to have discussed ACP with family and friends than are Calgaryans and other southern Albertans.
- Age, gender, income and education impact likelihood of having discussed ACP with family or friends. Seniors (70.4%), women (62.8%), upper income earners (60.9%) and post-secondary grads are most likely to have had those discussions. The youth (41.0%), men (51.6%), lower income earners (49.8%) and those without post-secondary credentials are the least likely to have discussed ACP with family or friends.

Region of Province	Calgary	Edmonton	North	South	All Alberta
Yes	55.5	59.5	60.1	53.3	57.0
No	44.5	40.5	39.9	46.7	43.0

Gender*	Male	Female	All Albertans
Agree	51.6	62.8	57.0
Disagree	48.4	37.2	43.0

Household Income*	Under \$60,000	\$60,000 to \$120,000	Over \$120,000
Agree	49.8	57.5	60.9
Disagree	50.2	42.5	39.1

Religious Participation	2-3 times/month-more	Several times/year	Rarely-never
Agree	54.4	54.6	57.2
Disagree	45.6	45.4	42.8

Education*	High School or less	Some Post-secondary	College-Tech-Trade	University Grad
Agree	47.6	55.8	58.9	61.8
Disagree	52.4	44.2	41.1	38.2

Age*	18-29	30-44	45-64	65 and older
Agree	41.0	54.4	60.3	70.4
Disagree	59.0	45.6	39.7	29.6

Notes: Due to rounding, proportions may not total exactly 100%; \* sig < 0.05

## Discussed Advance Care Plan with Doctor by Demographic Group (2013)(%)

- Despite their willingness to discuss advance care planning with family and friends, very few Albertans (16.5%) are taking the next step and having similar discussions with their doctors or other healthcare professionals.
- No significant regional variations are evident although southern Albertans outside of Calgary (13.2%) are even less likely than are other Albertans to have discussed advance care planning with a healthcare professional.
- Only age significantly impacts likelihood of discussing ACP with a healthcare professional, and only for seniors (28.3%) who are more than twice as likely to have done so as are all other age groups.

Region of Province	Calgary	Edmonton	North	South	All Alberta
Yes	17.9	16.5	17.5	13.2	16.5
No	82.1	83.5	82.5	86.8	83.5

Gender	Male	Female	All Albertans
Agree	15.1	18.2	16.5
Disagree	84.9	81.8	83.5

Household Income	Under \$60,000	\$60,000 to \$120,000	Over \$120,000
Agree	15.9	18.8	12.2
Disagree	84.1	81.2	87.8

Religious Participation	2-3 times/month-more	Several times/year	Rarely-never
Agree	16.2	15.4	16.7
Disagree	83.8	84.6	83.3

Education	High School or less	Some Post-secondary	College-Tech-Trade	University Grad
Agree	14.8	17.6	16.7	16.4
Disagree	85.2	82.4	83.3	83.6

Age*	18-29	30-44	45-64	65 and older
Agree	13.8	12.3	13.8	28.3
Disagree	86.2	87.7	86.2	71.7

Notes: Due to rounding, proportions may not total exactly 100%; \* sig < 0.05

## Have a Written Advance Care Plan by Demographic Group (2013) (%)

- Slightly less than one-third of Albertans (32.1%) currently have a written advance care plan.
- No significant regional variations are evident although southern Albertans outside of Calgary continue to lag behind the rest of the province.
- Age and gender significantly impact the likelihood of having a written ACP. Likelihood of having a written ACP increases with age, from only one in five young Albertans (20.4%) having a written ACP, to nearly half of all seniors (46.3%) having one. Women (36.5%) are somewhat more likely to have a written ACP than are men (27.8%). Other observed patterns concerning trends in education and income are also evident but those minor differences are not statistically significant on this item.

Region of Province	Calgary	Edmonton	North	South	All Alberta
Yes	33.6	29.9	39.0	26.9	32.1
No	66.4	70.1	61.0	73.1	67.9

Gender*	Male	Female	All Albertans
Agree	27.8	36.5	32.1
Disagree	72.2	63.5	67.9

Household Income	Under \$60,000	\$60,000 to \$120,000	Over \$120,000
Agree	25.1	34.2	31.2
Disagree	74.9	65.8	68.8

Religious Participation	2-3 times/month-more	Several times/year	Rarely-never
Agree	29.6	34.3	33.0
Disagree	70.4	65.7	67.0

Education	High School or less	Some Post-secondary	College-Tech-Trade	University Grad
Agree	28.4	28.5	33.9	34.9
Disagree	71.6	71.5	66.1	65.1

Age*	18-29	30-44	45-64	65 and older
Agree	20.4	24.5	35.1	46.3
Disagree	79.6	75.5	64.9	53.7

Notes: Due to rounding, proportions may not total exactly 100%; \* sig < 0.05

## Have a Written Personal Directive by Demographic Group (2013)(%)

- Nearly two of every five Albertans (39.4%) currently have a written personal directive (PD).
- No significant regional variations are evident although northern Albertans outside of Edmonton are more likely to have a written PD than are other Albertans.
- Age and gender significantly impact the likelihood of having a written PD. Likelihood of having a written PD increases with age, from only one in five young Albertans (21.5%) having a written PD, to well over half all seniors (57.1%) having one. Women (42.8%) are somewhat more likely to have a written PD than are men (36.1%).

Region of Province	Calgary	Edmonton	North	South	All Alberta
Yes	38.4	38.6	48.4	34.8	39.4
No	61.6	61.4	51.6	65.2	60.6

Gender*	Male	Female	All Albertans
Agree	36.1	42.8	39.4
Disagree	63.9	57.2	60.6

Household Income	Under \$60,000	\$60,000 to \$120,000	Over \$120,000
Agree	36.8	37.7	40.9
Disagree	63.2	62.3	59.1

Religious Participation	2-3 times/month-more	Several times/year	Rarely-never
Agree	39.0	40.5	40.2
Disagree	61.0	59.5	59.8

Education	High School or less	Some Post-secondary	College-Tech-Trade	University Grad
Agree	39.7	37.3	37.3	41.8
Disagree	60.3	62.7	62.7	58.2

Age*	18-29	30-44	45-64	65 and older
Agree	21.5	33.6	42.6	57.1
Disagree	78.5	66.4	57.4	42.9

Notes: Due to rounding, proportions may not total exactly 100%; \* sig < 0.05

## Heard of Goals of Care Designation by Demographic Group (2013) (%)

- Only about one in ten Albertans (11.1%) have heard of the term goals of care designation (GCD).
- No significant regional variations are evident although northern Albertans (7.9%) are the least likely to have heard the term while southern Albertans outside of Calgary are most likely (13.3%).
- No statistically significant differences between demographic groups are evident, although it is interesting to note that seniors (7.3%) are among the least likely to have heard the term goals of care designation.

Region of Province	Calgary	Edmonton	North	South	All Alberta
Yes	10.0	12.2	7.9	13.3	11.1
No	90.0	87.8	92.1	86.7	88.9

Gender	Male	Female	All Albertans
Agree	11.0	11.3	11.1
Disagree	89.0	88.7	88.9

Household Income	Under \$60,000	\$60,000 to \$120,000	Over \$120,000
Agree	8.6	13.8	13.9
Disagree	91.4	86.2	86.1

Religious Participation	2-3 times/month-more	Several times/year	Rarely-never
Agree	11.4	8.7	12.4
Disagree	88.6	91.3	87.6

Education	High School or less	Some Post-secondary	College-Tech-Trade	University Grad
Agree	6.9	12.1	13.4	11.2
Disagree	93.1	87.9	86.6	88.8

Age	18-29	30-44	45-64	65 and older
Agree	15.8	7.8	12.9	7.3
Disagree	84.2	92.2	87.1	92.7

Notes: Due to rounding, proportions may not total exactly 100%; \* sig < 0.05

## Demographics

Area of Province (%)		Gender (%)		Income (%)		Education (%)		Age (%)	
Calgary	33.4	Male	51.5	Under \$60,000	33.9	H-School/less	22.0	18-29	21.8
Edmonton	31.9	Female	48.5	\$60-\$120,000	40.8	Some P-Sec.	17.3	30-44	22.3
North	15.7			Over \$120,000	25.3	Col-Tech-Grad	26.9	45-64	34.7
South	19.0					University Grad	33.9	65 or older	21.2
									Mean age = 49 years old

Religious Participation (%)	
2-3/month-more	33.9
Several/year	40.8
Rarely-never	25.3

Note: Due to rounding, proportions may not total exactly 100%

## Questions

We would like to know how good or bad your health is today. Imagine a scale from 0 to 100 where 0 is the worst imaginable health and 100 is the best. What number would you use to describe your health today?

Have you ever heard of advance care planning?

Advance care plans are verbal or written instructions that make your wishes known about the kind of health care 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.” Based on this definition have you heard of advance care planning?

Have you had a discussion with family or a close friend about what healthcare treatment you want, or do not want, if you become very ill or injured and you cannot speak for yourself?

Have you ever had a discussion with a health care professional (e.g. doctor, nurse, social worker, or other healthcare team member) about what healthcare treatment you want or do not want if you become very ill or injured and you cannot speak for yourself?

Do you have an Advance Care Plan written down in any form or format?

Now we are going to ask you a question about personal directives. Personal directives are the legal documents in Alberta which allow you to name a decision maker and provide written instructions to guide your medical care, if due to illness or injury, you no longer have the capacity to make such decisions. Do you have a written Personal Directive?

Have you heard of the medical term “goals of care designations”?