Advance Care Planning

Alberta Public Opinion Study – February 2019

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Advance Care Planning – CSRL 2019 Alberta Study

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Methodology

Population: The province of Alberta has a total population of 4,334,025 residents (Statistics Canada, 2018) approximately 78% of which are 18 years of age or older for an adult population of 3,380,540.

Sample: Data were collected by Lethbridge College students in the winter of 2019. Students interviewed 1,055 adult Alberta residents by telephone from February 2 to 5, 2019 under the supervision of principal investigator Dr. Faron Ellis, Research Chair, Citizen Society Research Lab. Landline, hybrid and mobile telephone numbers were selected from a sample drawn from InfoGroup directories and supplemented by CSRL lists. 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

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, area of province and age).

Confidence: The weighted sample yields a margin of error \pm 3.0 percentage points, 19 times out of 20. The margin of error increases when analyzing sub-samples of the data (Calgary \pm 5.6 percentage points, Edmonton and immediate area \pm 5.8 percentage points, North \pm 6.3 percentage points, South \pm 6.3 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. We thank members of Lethbridge College's ITS and AV teams for their support in helping maintain the IB Commons Call Center.

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. These questions were derived from student and faculty interest in the topics.



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Executive Summary

Advance Care Planning – Albertans' Awareness and Preparation

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.

- Slightly less than one-third of Albertans (31.2%) have heard of advance care planning, prior to being provided a definition.
- When respondents were provided a definition that likened the term to a "living will," the three-quarters of Albertans (75.7%) stated they are familiar with the term.
- A majority of Albertans (59.1%) have discussed their own advance care planning with a family member or close friend.
- However, only one-fifth (20.4%) have also had those discussions with a healthcare professional.
- Nearly one-third of Albertans (32.6%) have a written advance care plan.
- More than two of every five Albertans (41.5%) have a written personal directive.
- Almost one in five Albertans (19.8%) have heard the medical term "goals of care designations," nearly double the 11.1% who had heard the term in 2013.

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 itemspecific results.

• Individuals interested in further information can contact the author of this study directly.



Seven Advance Care Planning Awareness and Preparation Items (%)

When queried about advance care planning, approximately one-third of Albertans (31.21%) are familiar with the term. Familiarity has increased considerably from 27.4% in 2015 and only 25.9% in 2013.

When ACP is associated with 'living wills' more than three-quarters of Albertans (75.7%) recognize the term, a level consistent with previous years.

A majority has discussed ACP with family (59.1%), a proportion that is consistent with previous years.

However, only one of every five (20.4%) have discussed the issue with a healthcare professional, a level that has increased only marginally from 16.5% in 2013.

Approximately one-third of Albertans (32.6%) have a written ACP, a level consistent with previous years.

Two of every five Albertans (41.5%) have a written personal directive, similar to levels measured in previous years.

Almost one in five Albertans (19.8%) are familiar with the term 'goals of care designation, considerably more than who were familiar with the term in 2013 (11.1%).

ACP Awareness and Preparation by Year (%)

	Heard of ACP	Heard of ACP (probe)	Discussed ACP with Family	Discussed ACP with HCP	Have Written ACP	Have Personal Directive	Heard of GCD
Alberta 2019	31.2	75.7	59.1	20.4	32.6	41.5	19.8
Alberta 2017	33.1	81.9	59.2	19.7	32.2	39.4	18.9
Alberta 2015	27.4	86.5	59.0	19.1	27.8	36.0	16.0
Alberta 2013	25.9	80.3	57.0	16.5	32.1	39.4	11.1



Seven Advance Care Planning Awareness and Preparation Items by Region of Alberta (%)

	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	31.2	75.7	59.1	20.4	32.6	41.5	19.8
Calgary	30.7	82.1	59.9	20.1	30.8	38.1	20.6
Edmonton	33.3	76.5	64.5	24.2	41.2	51.1	18.5
North	27.1	76.6	60.2	16.3	33.1	42.1	15.4
South	33.9	65.7	50.4	20.3	24.5	33.8	24.7

ACP Awareness and Preparation by Region of Alberta 2019 (%)

Note; * sig < 0.05

ACP Awareness and Preparation by Region of Alberta 2017 (%)

	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	33.1	81.9	59.2	19.7	32.2	39.4	18.9
Calgary	34.0	81.8	61.9	21.2	36.0	44.6	21.8
Edmonton	30.9	82.5	57.5	21.8	34.1	41.2	16.6
North	32.1	85.1	65.5	18.4	36.2	39.7	18.4
South	34.9	78.6	52.4	17.6	23.2	32.3	18.7

Note; * sig < 0.05

ACP Awareness and Preparation by Region of Alberta 2015 (%)

	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	27.4	86.5	59.0	19.1	27.8	36.0	16.0
Calgary	29.2	88.6	56.1	18.5	24.1	31.5	17.3
Edmonton	22.4	86.9	71.6	22.0	34.8	44.5	17.7
North	28.6	86.5	54.1	18.1	26.0	33.8	13.2
South	29.6	83.5	54.3	17.3	26.9	34.7	15.4

Note; * sig < 0.05



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 2.8, clearly less awareness/preparedness than the midpoint of the range (4.0).

As was partially indicated above, few regional differences on the items are measured. When combined, some minor differences emerge with Edmontonians (3.1) somewhat more aware than are other Albertans; Calgarians (2.8), northern Albertans (2.7) and southern Albertans, who are the least aware (2.5).

Gender has a significant impact on awareness/preparedness with women (3.0) more aware/prepared than men (2.6). Education impacts awareness/preparedness in that as education levels rise so too does awareness/preparedness. Religious Albertans (2.8) are slightly more aware/prepared than are less religious Albertans. Age is the most significant predictor of awareness and preparation. As age increases so too does awareness/preparedness, from a low of 1.8 among the youth to 3.7 for seniors.

For further explanation concerning the construction of the index or for a more extensive analysis, please contact the author.

Region*	<u>Calgary</u>	Edmonton	<u>North</u>	<u>South</u>	All Residents
	2.8	3.1	2.7	2.5	2.8
Gender*	Male	Female			
	2.6	3.0			
ncome*	<u>Under \$60,000</u>	<u>\$60-\$120,000</u>	<u>Over \$120,000</u>		
	2.4	2.9	2.9		
	2-3 per				
Religious Participation	month/more	<u>Several per year</u>	Rarely/never		
	2.8	2.6	2.7		
	High School or	Some Post-	College-Tech-		
Education*	Less	<u>secondary</u>	Trade	University Grad	
	2.4	2.4	2.9	3.1	
Age*	<u>18-29</u>	<u>30-44</u>	<u>45-64</u>	65 and older	
	1.8	2.4	3.0	3.7	

Advance Care Planning Awareness-Preparation Index 2017 (mean scores)

* sig < 0.05

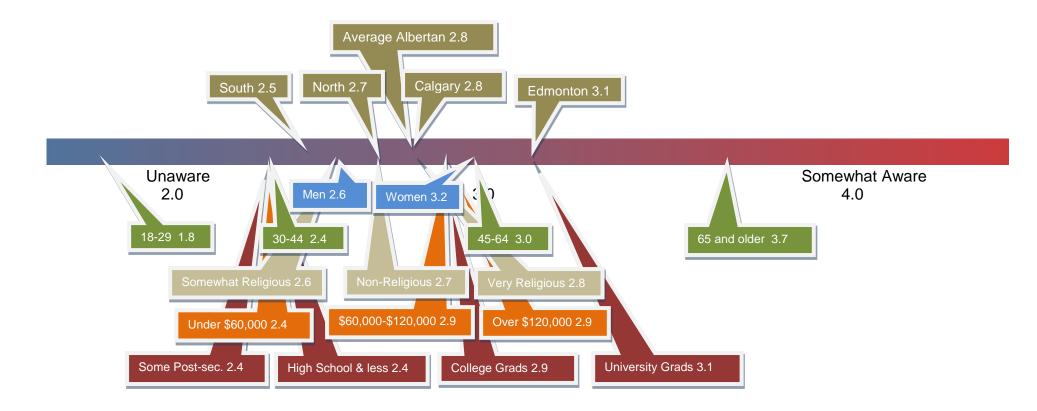
Range = 0 (uninformed-prepared) to 7 (informed-prepared)

Index of Advance Care Planning Awareness-Preparation

The graphic below provides a visual representation of the data presented on the previous page and indicates how 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 aware/prepared than are other groups.



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Heard of Advance Care Plan by Demographic Group (2019) (%)

When not provided with a definition, slightly less than one-third of Albertans (31.2%) recall having heard the term advance care planning (ACP).

No significant regional variations are evident although Edmontonians (33.9%) and southern Albertans outside of Calgary (33.9%) are somewhat more likely to have heard the term than are northern Albertans (27.1%) and Calgarians (30.7%).

Women (35.3%) are more familiar with ACP than are men (27.5%). Seniors (35.7%), those aged 45 to 64 years (35.3%), middle and upper-income, and well-educated Albertans are more familiar than are the youth (25.8%), lower-income (27.1%) and less well-educated Albertans.

Region of Province	Calgary	Edmonton	North	South	All Alberta
Yes	30.7	33.3	27.1	33.9	31.2
No	69.3	66.7	72.9	66.1	68.8
Gender*	Male	Female			
Yes	27.5	35.5			
No	72.5	64.5			
Household Income	Under \$60,000	\$60,000 to \$120,000	Over \$120,000		
Yes	27.1	33.4	29.7		
No	72.9	66.6	70.3		
Religious	2-3 times/month-more	Several times/year	Rarely-never		
Yes	30.8	28.2	32.4		
No	69.2	71.8	67.6		
Education*	High School or less	Some Post-secondary	College-Tech-Trade	University Grad	
Yes	24.1	29.4	33.4	34.7	
No	75.9	70.6	66.6	65.3	
Age	18-29	30-44	45-64	65 and older	
Yes	25.8	26.3	35.3	35.7	
No	74.2	73.7	64.7	64.3	

Heard of Advance Care Plan by Demographic Group – Probe with Definition (2019) (%)

When provided a definition that likened advance care plans to 'living wills', three-quarters of Albertans (5.7%) indicated they were familiar with the term ACP.

Gender, income, education and age impact awareness of ACP with the youth (54.2%) and poorer Albertans (64.6%) the least aware.

Women (84.0%) are more familiar with ACP than are men (68.7%), while university and college graduates are more familiar than are those without a post-secondary credential.

Upper-income Albertans (84.7%) are more familiar with ACP than are middle-income (80.1%) and lower-income (64.6%) residents.

Region of Province*	Calgary	Edmonton	North	South	All Alberta
Yes	82.1	76.5	76.6	65.7	75.7
No	17.9	23.5	23.4	34.3	24.3
Gender*	Male	Female			
Yes	68.7	84.0			
No	31.3	16.0			
Household Income*	Under \$60,000	\$60,000 to \$120,000	Over \$120,000		
Yes	64.6	80.1	84.7		
No	35.4	19.9	15.3		
Religious Participation	2-3 times/month-more	Several times/year	Rarely-never		
Yes	73.7	73.5	77.8		
No	26.3	26.5	22.2		
Education*	High School or less	Some Post-secondary	College-Tech-Trade	University Grad	
Yes	62.7	71.9	77.3	84.8	
No	37.3	28.1	22.7	15.2]
Age*	18-29	30-44	45-64	65 and older	_
Yes	54.2	77.2	84.4	84.5	
No	45.8	22.8	15.6	15.5	



Discussed Advance Care Planning with Family by Demographic Group (2019) (%)

A clear majority of Albertans (59.1%) have discussed advance care plans with family members or a close friend. Edmontonians (64.5%) are slightly more likely than are other Albertans to have disused ACP with family and friends.

Women (64.1%) are more likely than are men (55.0%) to have had an ACP discussion with family or friends. Upper-income (67.0%) and middle-income (59.5%) Albertans are more likely to have had an ACP discussion with family or friends than are lower-income Albertans (52.1%).

Most significantly, seniors (78.8%) are most likely to have had an ACP discussion with family or friends. Likelihood of having had a discussion decreases with age, to a low of only two of every five youth (39.4%) having had an ACP discussion with family or friends.

Region of Province*	Calgary	Edmonton	North	South	All Alberta
Yes	59.9	64.5	60.2	59.9	59.1
No	40.1	35.5	39.8	40.1	40.9
Gender*	Male	Female			
Yes	55.0	64.1			
No	45.0	35.9			
Household Income*	Under \$60,000	\$60,000 to \$120,000	Over \$120,000		
Yes	52.1	59.5	67.0		
No	47.9	40.5	33.0		
Religious Participation	2-3 times/month-more	Several times/year	Rarely-never		
Yes	58.2	56.4	60.6		
No	41.8	43.6	39.4		
Education	High School	Some Post-secondary	College-Tech-Trade	University Grad	
Yes	60.4	53.9	57.4	63.5	
No	39.6	46.1	42.6	36.5	
Age*	18-29	30-44	45-64	65 and older	
Yes	39.4	54.2	61.7	78.8	
No	60.6	45.8	38.3	21.2	

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



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Discussed Advance Care Plan with Healthcare Professional by Demographic Group (2019) (%)

Despite their willingness to discuss advance care planning with family and friends, only about one of every five Albertans (20.4%) have had a similar discussion with their physician or other healthcare professionals.

No significant regional variations are evident. Edmontonians are most likely and northern Albertans outside of Edmonton are least likely to have had an advance care planning discussion with a healthcare professional.

Men (20.2%) are just as likely as are women (20.8%) to have had an ACP discussion with a healthcare professional.

Highly-religious Albertans (22.1%), lower-income Albertans (22.6%) and seniors (33.5%) are slightly more likely to have had an ACP discussion with a healthcare professional than are less religious, more educated and younger Albertans.

Region of Province	Calgary	Edmonton	North	South	All Alberta
Yes	20.1	24.2	16.3	20.3	20.4
No	79.9	75.8	83.8	79.7	79.6
Gender	Male	Female			
Yes	20.2	20.8			
No	79.8	79.2			
Household Income*	Under \$60,000	\$60,000 to \$120,000	Over \$120,000	_	
Yes	22.6	19.3	14.2		
No	77.4	80.7	85.8		
Religious Participation	2-3 times/month-more	Several times/year	Rarely-never	_	
Yes	22.1	17.6	19.0		
No	77.9	82.4	81.0		
Education	High School or less	Some Post-secondary	College-Tech-Trade	University Grad	
Yes	24.9	12.8	21.3	21.9	
No	75.1	87.2	78.7	78.1	
Age*	18-29	30-44	45-64	65 and older	
Yes	15.0	12.8	19.0	33.5	
No	85.0	87.2	81.0	66.5	

Have a Written Advance Care Plan by Demographic Group (2019) (%)

Nearly one-third of Albertans (32.6%) currently have a written advance care plan. Only minor significant regional variations are evident although Edmontonians (41.2%) are slightly more likely to have a written plan while southern Albertans outside of Calgary (24.5%) are less likely than are other Albertans to have a written plan.

Women (34.6%) are only slightly more likely than are men (31.2%) to have a written ACP. Middle-income (33.8%) and upper-income (40.1%) Albertans are more likely than are lower-income Albertans (24.1%) to have a written plan. University graduates (39.6%) are more likely than are other Albertans to have written plans. Highly-religious Albertans (36.4%) are slightly more likely than are other Albertans to have a written plans. Highly-religious Albertans (36.4%) are slightly more likely than are other Albertans to have a written plans.

As age increases, so does the likelihood of having a written ACP. A majority of seniors (55.2%) have a written plan while very few young Albertans (8.1%) have written advance care plans.

Region of Province	Calgary	Edmonton	North	South	All Alberta
Yes	30.8	41.2	33.1	24.5	32.6
No	69.2	58.8	66.9	75.5	67.4
Gender	Male	Female			
Yes	31.2	34.6			
No	68.8	65.4			
Household Income*	Under \$60,000	\$60,000 to \$120,000	Over \$120,000		
Yes	24.1	33.8	40.1		
No	75.9	66.2	59.9		
Religious Participation*	2-3 times/month-more	Several times/year	Rarely-never	_	
Yes	36.4	30.3	28.9		
No	63.6	69.7	71.1		
Education*	High School or less	Some Post-secondary	College-Tech-Trade	University Grad	
Yes	27.0	23.6	34.9	39.6	
No	73.0	76.4	65.1	60.4	
Age*	18-29	30-44	45-64	65 and older	_
Yes	8.1	25.4	38.3	55.2	
No	91.9	74.6	61.7	44.8	



Have a Written Personal Directive by Demographic Group (2019) (%)

Slightly more than two of every five Albertans (41.5%) currently have a written personal directive. A majority of Edmontonians (51.1%) have a written personal directive while only one-third of southern Albertans living outside of Calgary (33.8%) have a written personal directive.

Men (41.7%) are just as likely as are women (41.9%) to have a written personal directive. Middle-income (44.2%) and upper-income (45.4%) Albertans are more likely to have a written personal directive than are lower-income Albertans (32.6%).

Highly-religious Albertans (44.4%) are slightly more likely to have a written personal directive than are moderately-religious (42.9%) and non-religious (36.4%) Albertans. University graduates (46.3%) are more likely than are other Albertans to have a written personal directive than are other Albertans.

A substantial majority of Alberta seniors (68.7%) have a written personal directive. Likelihood of having a written personal directive decreases with age, to a low of only 14.6% among the youth.

Region of Province*	Calgary	Edmonton	North	South	All Alberta
Yes	38.1	51.1	42.1	33.8	41.5
No	61.9	48.9	57.9	66.2	58.5
Gender	Male	Female			
Yes	41.7	41.9			
No	58.3	58.1			
Household Income*	Under \$60,000	\$60,000 to \$120,000	Over \$120,000		
Yes	32.6	44.2	45.4		
No	67.4	55.8	54.6		
Religious Participation*	2-3 times/month-more	Several times/year	Rarely-never		
Yes	44.4	42.9	36.1		
No	55.6	57.1	63.9		
Education*	High School or less	Some Post-secondary	College-Tech-Trade	University Grad	
Yes	38.4	32.3	44.7	46.3	
No	61.6	67.7	55.3	53.7	
Age*	18-29	30-44	45-64	65 and older	_
Yes	14.6	32.5	46.2	68.7	
No	85.4	67.5	53.8	31.3	



Heard of Goals of Care Designation by Demographic Group (2019) (%)

Only about one in five Albertans (19.8%) have heard the term goals of care designation (GCD).

No significant regional variations are evident although Calgarians (20.6%) and other southern Albertans (24.7%) are slightly more likely to have heard the term than are other Albertans

Women (25.0%) are more likely to have heard the term GCD than are men (14.8%). Lower-income Albertans (20.7%) are slightly more likely than are upper-income (15.5%) and middle-income (18.8%) Albertans to have heard the term GCD. University graduates (23.7%) are more likely to have heard the term GCD than are other Albertans.

Interesting, age does not have a significant impact on awareness of the term GCD, although young Albertans (23.9%) are slightly more likely to have head the term than are seniors (16.2%).

Region of Province	Calgary	Edmonton	North	South	All
Yes	20.6	18.5	15.4	24.7	19.8
No	79.4	81.5	84.6	75.3	80.2
Gender*	Male	Female			
Yes	14.8	25.0			
No	85.2	75.0			
Household Income	Under \$60,000	\$60,000 to \$120,000	Over \$120,000		
Yes	20.7	18.8	15.5		
No	79.3	81.2	84.5		
Religious Participation	2-3 times/month-more	Several times/year	Rarely-never		
Yes	23.5	14.5	19.9		
No	76.5	85.5	80.1		
Education*	High School or less	Some Post-secondary	College-Tech-Trade	University Grad	
Yes	9.8	23.4	19.9	23.7	
No	90.2	76.6	80.1	76.3	
Age	18-29	30-44	45-64	65 and older	_
Yes	23.9	17.1	21.4	16.2	
No	76.1	82.9	78.6	83.8	



Demographics (%)

Area of Province		Gender		Income		Education		Age	
Calgary	26.2	Male	49.8	Under \$60,000	37.5	H-School/less	19.8	18-29	22.9
Edmonton	24.1	Female	49.5	\$60-\$120,000	39.1	Some P-Sec.	21.1	30-44	23.2
North	23.4	Other	0.7	Over \$120,000	23.5	Col-Tech-Grad	28.8	45-64	31.0
South	26.4					University Grad	30.3	65 or older	22.9

Mean age = 48 years

Religious Participation				
2-3/month-more	26.1			
Several/year	19.4			
Rarely-never	54.5			

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

Questions

- 1) Have you ever heard of advance care planning?
- 2) 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?
- 3) 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?
- 4) 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?
- 5) Do you have an Advance Care Plan written down in any form or format?
- 6) 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?
- 7) Have you heard of the medical term "goals of care designations"?
 - ∘ Yes
 - **No**
 - o don't know (unprompted)
 - refused (unprompted)



