

Background

- There is a growing population of childhood cancer survivors (CCS) who need ongoing medical surveillance.
- CCS are likely at elevated risk for being underinsured.
- The 2010 Affordable Care Act (ACA) was established to improve access to affordable healthcare, including provisions that prohibit preventive care co pays, promote primary care, and ban pre-existing conditions exclusions.
- CCS' coverage preferences & familiarity with the ACA are unknown.

Study Objectives

- 1) Examine survivors' and siblings' familiarity with the ACA and other health insurance related legislation.
- 2) Examine survivors' and siblings' concerns and hopes about the ACA.
- 3) Determine survivors' & siblings priorities for insurance coverage

Methods

- The Childhood Survivor Study (CCSS) is a retrospective cohort of cancer patients diagnosed 1970-1986 ≤21 years (N=14,370) & a random sample of siblings (N=3418).
- We surveyed a randomly-selected, age-stratified sample of 698 survivors & 210 siblings from CCSS
- Data collection was from May 2011 to April 2012.
- We achieved participation rates of 71% (survivors) and 65% (siblings).
- Content analysis compared write-in concerns & hopes about the ACA.
- Means & proportions compared using t-tests & chi-square analyses.

Participants

	Survivors N=698	Siblings N=210	p value
	%	%	
Age at survey (years)			0.24
22-29	30.7	29.1	
30-39	32.7	32.4	
40-62	28.8	26.2	
Gender			0.13
Male	45.0	39.1	
Race/Ethnicity			.52
White	92.8	92.5	
Black	2.0	2.0	
Hispanic/Latino	3.5	3.0	
Education (as of 2007 survey)			0.12
≤High school	15.6	9.9	
Some college	28.5	26.6	
Completed college and above	56.0	63.5	
Marital Status			0.01
Single (never married)	34.7	23.4	
Married, living as married	56.8	67.5	
Employed (full/part-time)	74.0	78.7	0.13

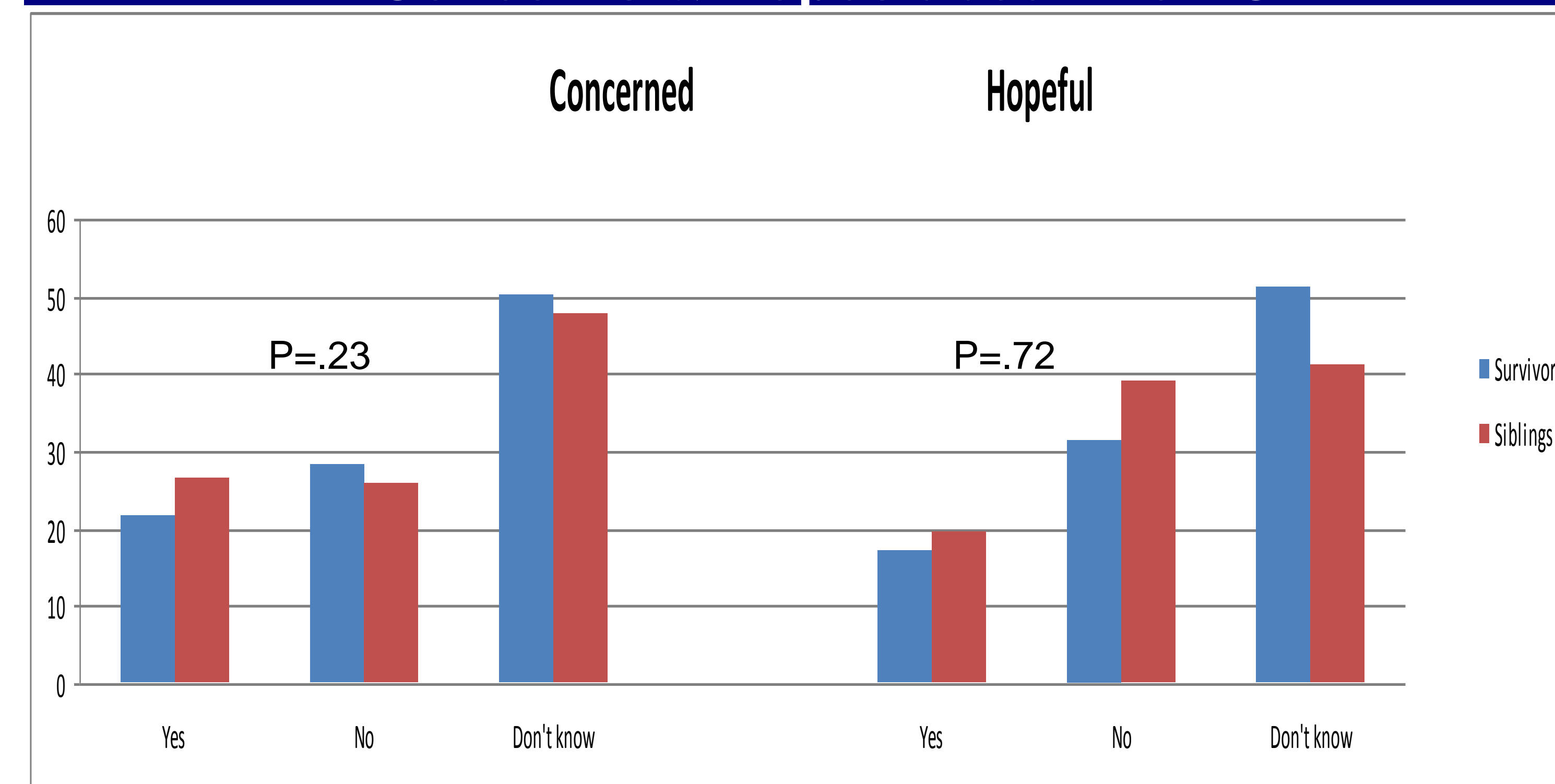
Survivors were significantly less likely than siblings to be married, employed, and have a household income >\$80,000

Participants

Cancer Diagnosis	%	Survivors N=698	Siblings N=210	p value
		%	%	
Leukemia	37.0			
Central Nervous System	14.9			
Hodgkin lymphoma	10.2			
Age at Diagnosis (years)				
0-4	52.3			
5-10	14.9			
11-15	15.6			
16-20	11.6			
Years since Diagnosis				
22-29	56.3			
30-35	23.1			
≥35	20.6			
Second cancer/Recurrence				
None	84.2			
Second cancer	3.3			
Recurrence	11.5			
HEALTH INSURANCE				.59
Insured		88.7	90.0	
Uninsured		11.3	10.0	
POLICY OWNER				.48
Self		71.2	68.8	
Spouse		22.6	26.8	
Parent		5.3	3.9	
TYPES OF INSURANCE				.001
Employer Sponsored		74.8	83.9	
Individual		7.3	10.2	
Medicare		3.5	0.5	
Medicaid/State		13.5	4.9	
RATINGS OF INSURANCE				.24
Excellent			20.3	
Very Good			33.8	
Good			30.9	
Fair/Poor			13.1	

•Fewer than 10% of survivors had been diagnosed with: NHL, Wilms Tumor, Neuroblastoma, Soft Tissue Sarcoma and Bone.
•More than half were age 0-4 at diagnosis.
•More than half were 22-29 years post-diagnosis.

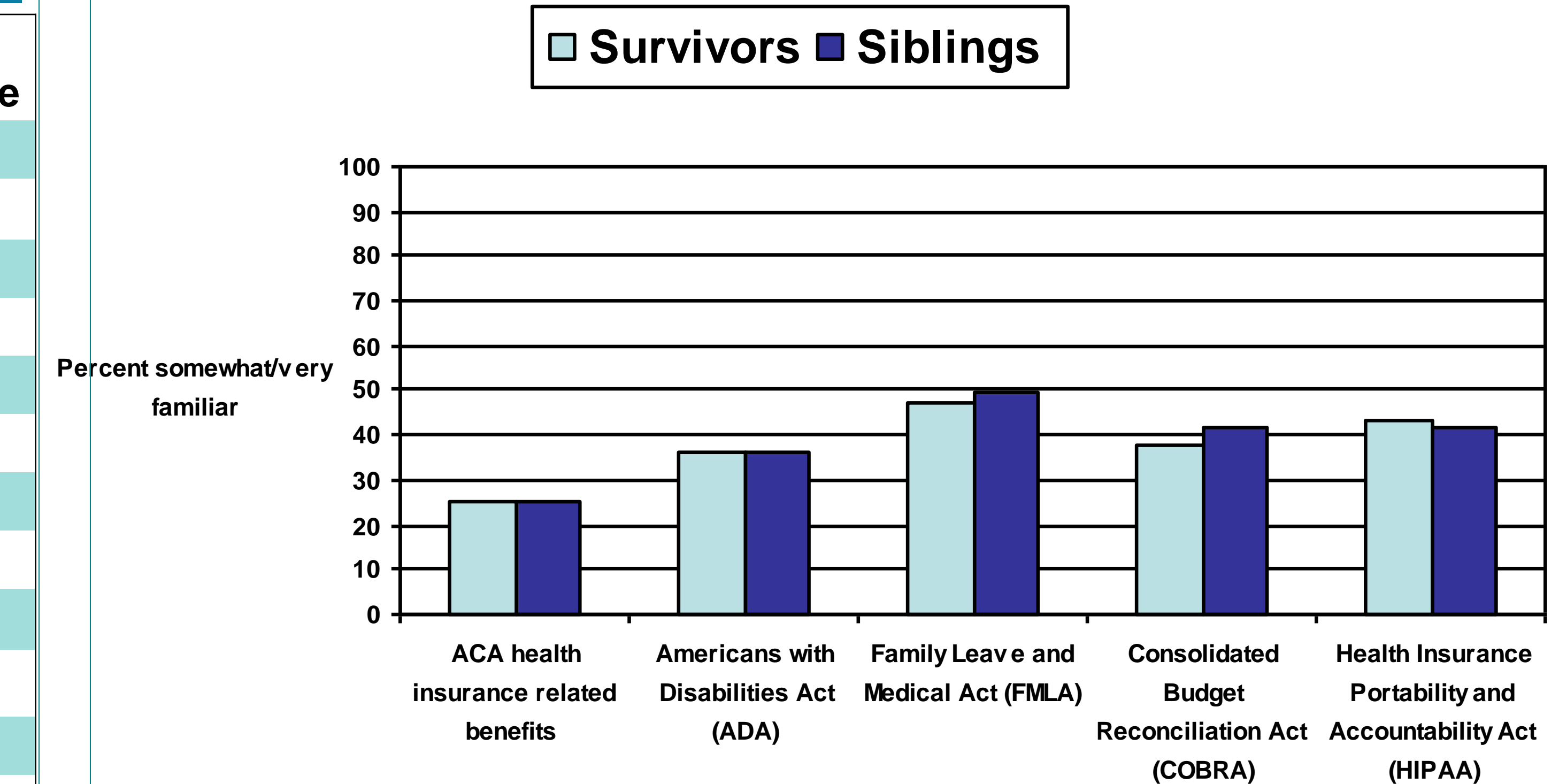
Concerns & Hopes about the ACA



CONCERNS	HOPES
Cost of Coverage	Cost of Coverage
Insurance Coverage	Insurance Coverage
Access to Care	Access to Care
Quality of Care	Quality of Care
Government Involvement	Government Involvement
Impact on Employer/ESI	---

Less than 20% of CCS & siblings were hopeful about the ACA; approximately half did not know whether to feel hopeful or concerned. Similar factors elicited both concern and hope.

Familiarity with health-insurance related legislation



Importance of Plan Coverage, Features & Cost

	Survivors N=698	Siblings N=210	p value
	%	%	
PLAN COVERAGE			
Primary Care	94.3	89.7	.02
Dental Care	67.4	65.8	.22
Vision Care	60.7	50.0	.01
PLAN FEATURES			
No Waiting Period	79.0	69.0	.01
Choice of PCP	76.5	66.7	.01
Ability to Self Refer	55.7	50.0	.15
PLAN COST			
Affordable premiums	88.1	83.7	.10
No added expense-PEC	87.2	69.8	.01
Low Deductible	73.8	66.2	.01

CCS & siblings ranked importance for plan coverage, features & cost factors as similarly important. However, a higher portion of CCS endorsed these features than siblings.

Conclusions

- Over half of CCS did not even know whether to feel concerned or hopeful about benefits/protections under the ACA.
- CCS and siblings demonstrated a lack of familiarity with the ACA and health-related legislation.
- CCS' coverage preferences match many ACA provisions, education & assistance on how the ACA is personally relevant will likely be needed for CCS to access & benefit from ACA provisions.

Funding

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