

# The ACA and Health Insurance Challenges faced by AYA

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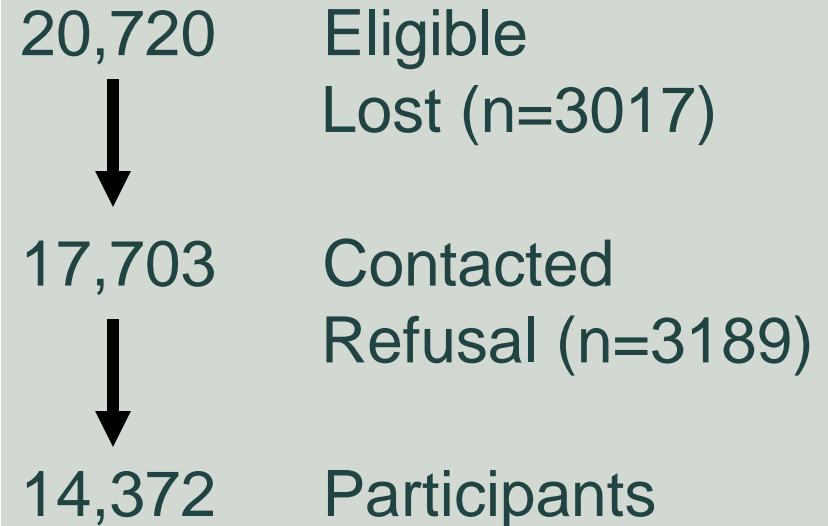
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- Funded in 1994
- Retrospective Cohort, diagnosed 1970-1986
- 26 Contributing Centers
- 5-Year Survival (median age=23yrs, range 5-45)
- Leukemia, Lymphoma, CNS, Bone, Wilms, NBL, Soft-tissue sarcoma
- Detailed Treatment Data, Wide Range of Outcomes



# Background

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- ❑ CCS = ages 0 up to 21 years
- ❑ CCS are at risk for being uninsured (88 vs 91% survivors v. siblings) & may be at risk for being underinsured (Park et al., JCO, 2005)
- ❑ Quality health insurance is critical for survivors
- ❑ Uninsured CCS are at risk for not receiving recommended survivorship care (Casillas, 2011)



# Health Care Reform's Potential for Young Adults (Collins et al., TCF, 2011)

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- ❑ Young adults are at risk of being uninsured
- ❑ In 2009, almost one-third of young adults 19-29 did not have coverage; half are 133% under the FPL
- ❑ In 2011, decrease in percentage of young adults uninsured
- ❑ Almost half of young adults reported forgoing medical care because of cost



# Background & Rationale

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- ❑ 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.
- ❑ Coverage preferences & familiarity with the ACA are unknown.



# ACA favorable outcomes for young cancer survivors

(Wolfson, 2010, The Cancer Journal )

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- ❑ Prohibits coverage denial due to a pre-existing condition
- ❑ Allows children to stay on their parents policy until age 26
- ❑ Expanded Medicaid eligibility to people up to 133% of Federal Poverty Level (\$29,700/family of 4)
- ❑ Requires coverage of recommended preventive care
- ❑ Promotion of primary care
- ❑ Establishment of temporary high risk pools
- ❑ Prevents group health plans from imposing lifetime limits



# Study Design: CCSS collaboration

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- **Phase 1:** qualitative exploration
- **Phase 2:** survey comparing survivors and siblings
  - Survey development drew from: National Health Interview Survey, Children with Special Health Care Needs, Medical Expenditure Survey, Community Tracking Survey, & Kaiser/CWF National Survey of Health insurance





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# PHASE 1



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# Phase 1 Aims

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- To qualitatively explore and CCS' & siblings':
  - Perceived quality of coverage
  - Coverage needs and difficulties
  - Knowledge of existing health-insurance related legislation



# Phase 1 Data Collection & Analysis

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- ❑ Random selection, stratifying by age ( $\leq 30$  years,  $>30$  years) and health insurance status (uninsured, insured)
- ❑ Semi-structured interview guide
- ❑ In-depth interviews from 9/09-2/10
- ❑ Interviews were recorded and transcribed
  - Thematic content analyses
  - 2 independent coders using NVivo 8 (Kappa=0.88)
- ❑ Sociodemographic & medical data obtained from CCSS baseline and 2007 surveys



# Baseline Characteristics (n=39)

≤ 30 years at interview	54%
Gender female	49%
White, non-Hispanic	74%
< College education	54%
<\$20,000 household Income	40%
Marital Status	
Single	46%
Married/Living as Married	49%
Second Malignancy/Recurrence	18%



# Uninsured survivors' current impressions and future concerns

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- ❑ Little concern about current lack of coverage
- ❑ Coping by avoiding and/or minimizing need for care
  - *“I just don’t think of it. It’s just not something that I try to worry about.”*
- ❑ Some had concerns about future health, obtaining coverage, and costs
  - *“Yeah, it does concern me that, you know, if something happens...Nobody’s going to give me insurance. That’s a pre-existing condition and a million dollars worth of bills.”*



# Insured survivors' satisfaction with current coverage

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- ❑ Overall satisfaction with services covered but low expectations
  - *“I’m glad I have insurance.”*
- ❑ Reluctance to complain or seem ungrateful
  - *“It could be better. It gets more expensive every year and has less coverage.”*
- ❑ Dissatisfaction with costs; over half reported annual out of pocket costs >\$2,000
  - *“We have a huge deductible because we’re paying, you know, like a thousand a month... But that’s all we could do, we both have pre-existing conditions.”*



# Insured survivors' difficulties obtaining and using coverage

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- Frustrated by process of getting coverage
  - “I was so just kind of flabbergasted when I went to try and get insurance on my own...I thought it would be a simple easy experience and I was severely wrong...”
  
- Difficulties understanding and using current coverage
  - *“I don’t even know what is covered because I tried reading the booklet and of course I don’t understand all the language in it.”*



# Survivor coverage preferences

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- Both uninsured and insured survivors prioritized the need for coverage for routine care services and physician choice
- Half of insured survivors emphasized the importance of having no exclusions/denials due to pre-existing conditions
  - *"I don't think (survivors) should be discriminated against for pre-existing conditions. I think it's important that (survivors) receive follow up..."*





# Concerns about future coverage

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- ❑ Worry about coverage costs increasing or loss of coverage in the future
  - *"Next year I have to have so many hours to have insurance and I may not have enough hours, you know, that are worked so that's what I'm concerned about."*
- ❑ Worry that costs would become burdensome
  - *"Yeah, yeah a little bit I'm worried that down the road that if it keeps getting to be so expensive that we will eventually have to start cutting back and changing our lifestyle."*
- ❑ Many uninsured & insured survivors feared future coverage problems if/when a "health catastrophe" hit



# Knowledge of health insurance-related legislation and resources

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- ❑ Overall lack of knowledge about existing insurance legislation
- ❑ Almost all participants expressed interest in an educational program to learn how to obtain and better understand coverage and learn about their legal rights and protection against discrimination



# Phase 1 Main Findings

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- ❑ Uninsured survivors minimized their need for care
- ❑ Many insured survivors had difficulty obtaining & utilizing their coverage
- ❑ Insured survivors had low coverage expectations
- ❑ Salient fear of “health catastrophe” and future loss of coverage/unaffordable care
- ❑ Lack of knowledge about insurance-related rights & protections



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# PHASE 2



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# Objectives

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1. Examine impressions of current coverage
2. Determine priorities for insurance coverage.
3. Examine familiarity with the ACA and other health insurance-related legislation.
4. Examine impressions about the ACA.



# Survey Content

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- Current coverage & coverage history
- Current Employment
- Health Care Utilization
- Coverage Quality
- Health Care Reform & Insurance-Related Protections



# Phase 2 Data Collection

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- ❑ Random sampling of U.S. CCSS participants, stratified by age (<30, 30-39, 40+)
- ❑ Insured and uninsured survey versions
- ❑ Mailed and internet completion options
- ❑ Final sample: 699 survivors & 211 siblings
- ❑ Survivors: 64% response rate & 70% participation rate
- ❑ Siblings: 59% response rate & 65% participation rate



# LTFU

Long-Term Follow-Up Study

## Health Insurance Survey

### Currently Insured Persons

The following questions are for currently insured persons. If you currently do not have health insurance, please fill out the yellow survey.

You can be assured that we will respect your privacy at all times. Your name or other identifiers will not be used in any report of our findings, or released to any person or agency, except study investigators.

Your generosity in participating is greatly appreciated.

Sincerely,

The LTFU study staff

### Currently Uninsured Persons

The following questions are for currently uninsured persons. If you currently have health insurance, please fill out the green survey.

You can be assured that we will respect your privacy at all times. Your name or other identifiers will not be used in any report of our findings, or released to any person or agency, except study investigators.

Your generosity in participating is greatly appreciated.

Sincerely,

The LTFU study staff

**Do you currently have health insurance that covers doctor and hospital care?**

Yes → If Yes, please proceed to Question 1 on the next page.

No → If No, please stop and complete the Yellow survey.

**Do you currently have health insurance that covers doctor and hospital care?**

Yes → If Yes, please stop and complete the Green survey.

No → If No, please proceed to Question 1 on the next page.



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**36. Think about your ideal health insurance plan. Please rate how important each of the following health insurance features are for you:**

	Very important	Somewhat important	Not too important	Not at all important
a. Coverage for primary care . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Coverage for acute, cancer-specific care (e.g., cancer recurrence or new cancer) .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Coverage for acute, non-cancer-specific care (e.g., emergency room visits) . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Coverage for mental health care . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Coverage for dental care . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Coverage for vision care . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Choice of your primary care physician . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Ability to self-refer to a specialist . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Low deductible (i.e., the money you pay before insurance starts to make payments for covered medical services) .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. Low co-pay (i.e., the money you pay each time you get a medical service) . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. Affordable premiums (i.e., the money you pay to have coverage, usually paid monthly) . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l. No coverage limits (lifetime or annual). .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m. No added expense due to pre-existing conditions . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n. No waiting period before coverage begins . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



	<b>Survivors</b>	<b>Siblings</b>	<b>p value</b>
	%	%	
<b>Age at survey (years)</b>			0.24
22-29	30.7	29.1	
30-39	32.7	32.4	
40-62	36.6	38.5	
<b>Male Gender</b>	45.0	39.1	0.13
<b>Race/Ethnicity</b>			.52
White	92.8	92.5	
Black	2.0	2.0	
Hispanic/Latino	3.5	3.0	
<b>Education (2007 survey)</b>			0.12
≤High school	15.5	9.9	
Some college	28.5	26.6	
Completed college and +	56.0	63.5	
<b>Married, living as married</b>	56.8	67.5	0.01
<b>Employed (full/part-time)</b>	74.0	78.7	0.13

<b>Cancer Diagnosis</b>	<b>%</b>
Leukemia	37.0
Central Nervous System	14.9
Hodgkin lymphoma	10.2
Other	37.9
<b>Age at Diagnosis (years)</b>	
0-4	52.3
5-10	14.9
11-15	15.6
16-20	11.6
<b>Years since Diagnosis</b>	
22-29	56.3
30-35	23.1
≥35	20.6
<b>Second cancer/Recurrence</b>	
None	84.2
Second cancer	3.3
Recurrence	11.5



## Health Insurance Characteristics

	<b>Survivors</b>	<b>Siblings</b>	<b>p value</b>
<b>INSURANCE STATUS</b>	%	%	.59
Insured	88.7	90.0	
Uninsured	11.3	10.0	
<b>POLICY OWNER</b>			.48
Self	71.2	68.8	
Spouse	22.6	26.8	
Parent	5.3	3.9	
<b>INSURANCE TYPE</b>			.001
Employer Sponsored/Military	74.8	83.9	
Individual	7.3	10.2	
Medicare	3.5	0.5	
Medicaid/State	13.5	4.9	
<b>INSURANCE RATINGS</b>			.24
Excellent	23.0	20.3	
Very Good	34.4	33.8	
Good	23.9	30.9	
Fair/poor	17.0	13.1	

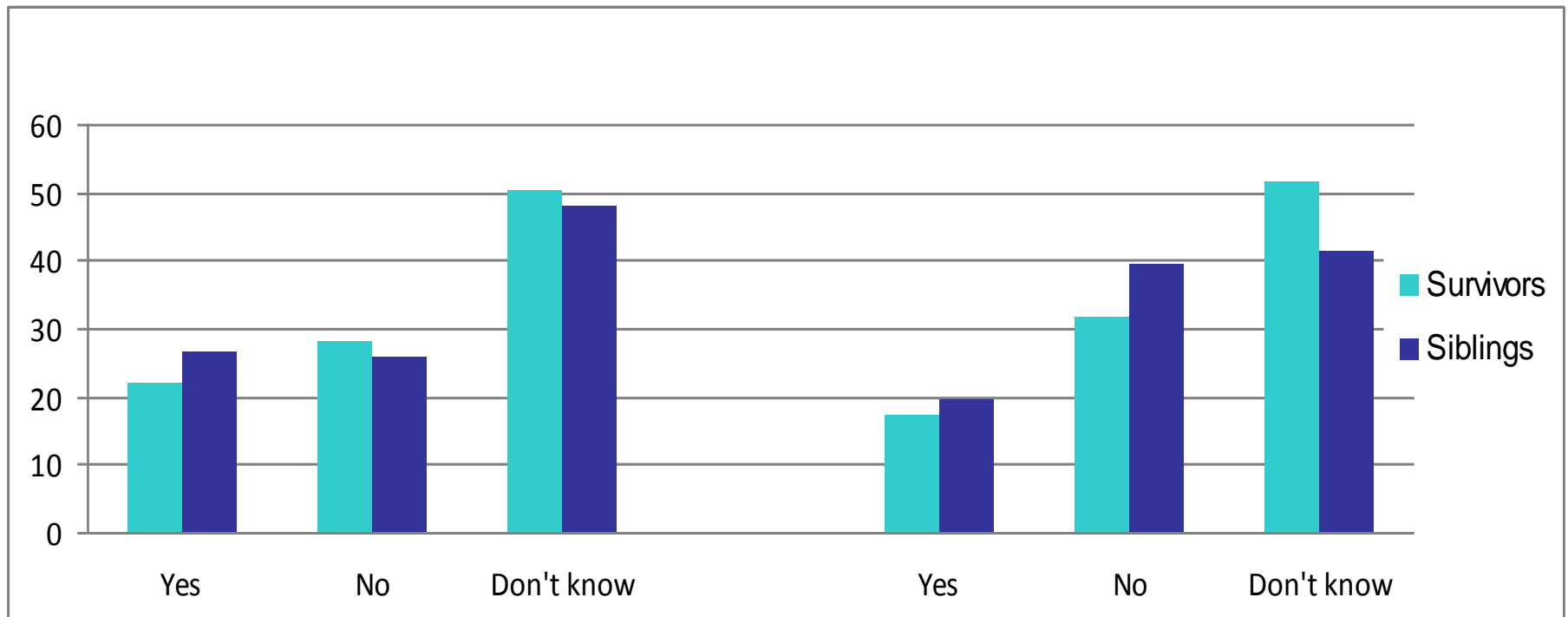
# Health Insurance Characteristics

	<b>Survivors</b>	<b>Siblings</b>	<b>p value</b>
<b>Willingness to Pay/month (individual) Mean (sd)</b>	211 (319.9)	203 (147.7)	0.77
<b>Willingness to Pay/month (family) Mean (sd)</b>	418 (435.4)	416 (339.4)	0.96
<b>EVER BEEN DENIED:</b>			
<b>Health Insurance (%)</b>	14.7	1.9	0.001
<b>Dental insurance (%)</b>	3.0	0.0	0.001
<b>Vision insurance (%)</b>	2.1	0.0	0.001
<b>DIFFICULTY OBTAINING COVERAGE (2 Years)</b>	6.7	1.0	.001

# Importance of Plan Coverage, Features, and Cost

	Survivors	Siblings	p value
	%	%	
<b>PLAN COVERAGE</b>			
Primary Care	94.3	89.7	.02
Dental Care	67.4	65.8	.22
Vision Care	60.7	50.0	.01
<b>PLAN FEATURES</b>			
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
<b>PLAN COST</b>			
Affordable premiums	88.1	83.7	.10
No added expense-PEC	87.2	69.8	.01
Low Deductible	73.8	66.2	.01

# Concerns & Hopes About the ACA



Less than 20% of survivors and siblings were hopeful about the ACA.



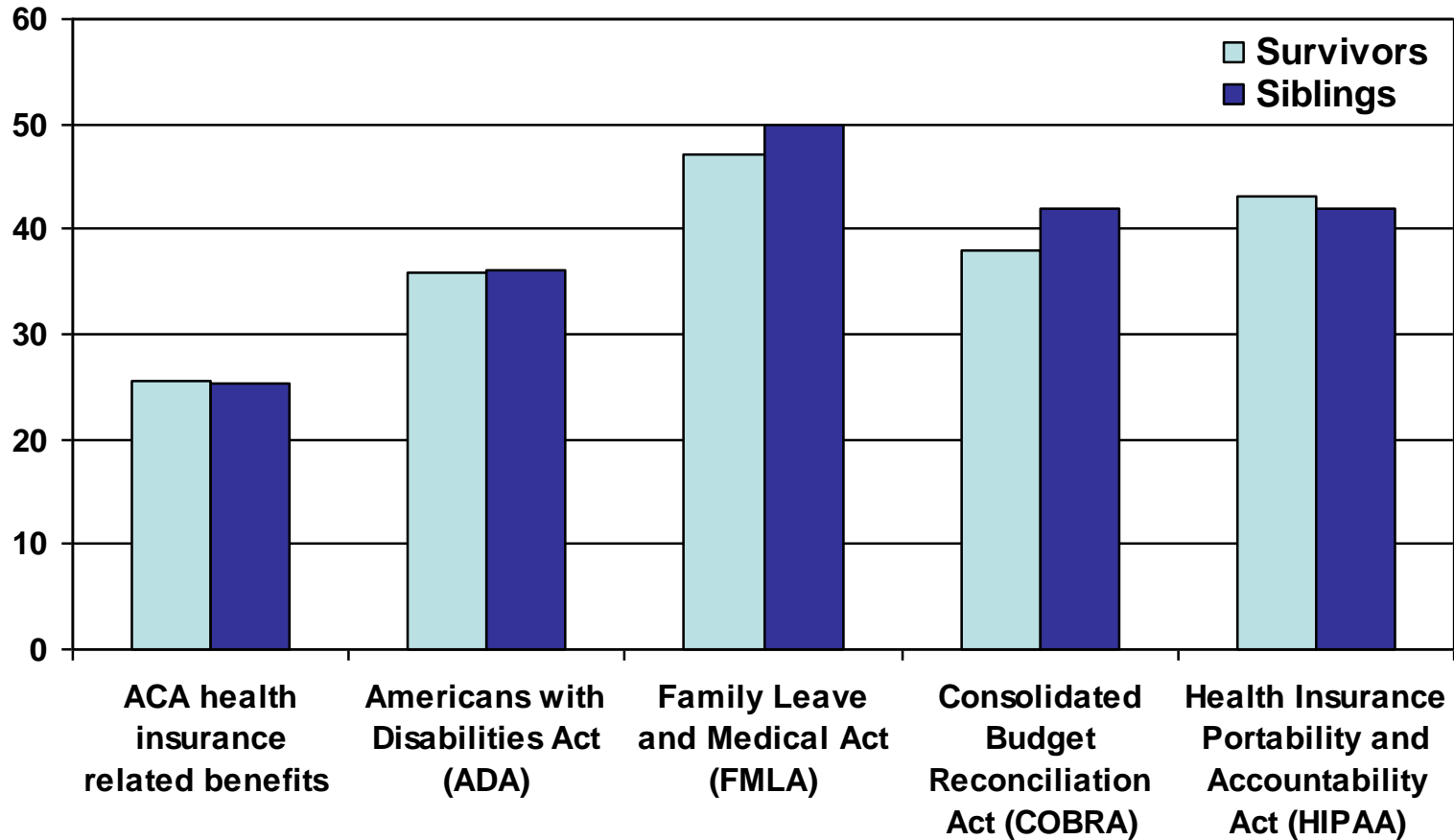
# Concerns & Hopes About the ACA

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

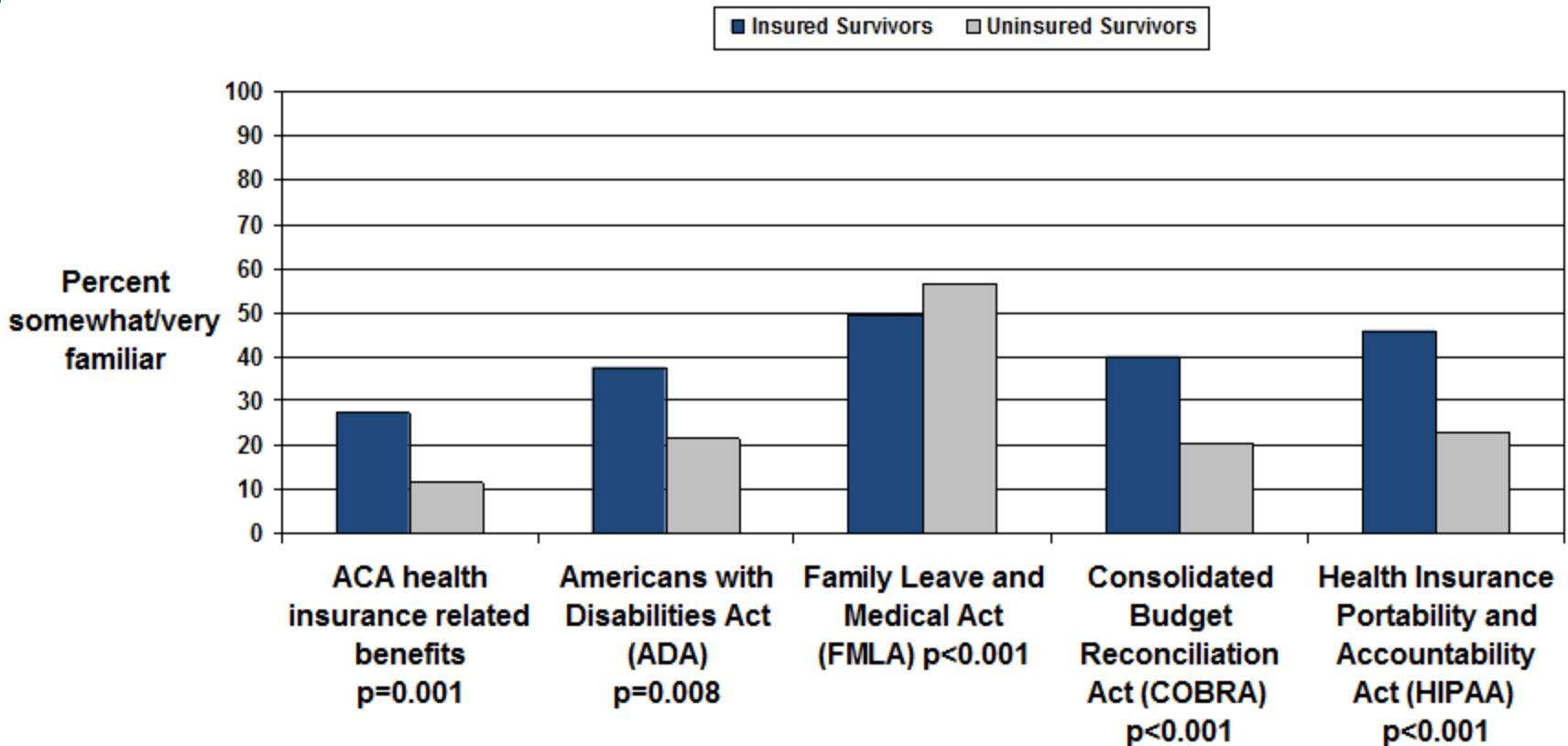




# Familiarity with Health Insurance-Related Legislation



# Familiarity with Health Insurance-Related Legislation



# Coverage Conclusions

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- ❑ Survivors were less likely to be covered by ESI
- ❑ Survivors were more likely to have had difficulties obtaining coverage
- ❑ Survivors and siblings similarly rated coverage
- ❑ Survivors and siblings ranked importance for plan coverage, features and cost factors as similarly important. However, a higher portion of CCS endorsed these features than siblings



# Implications for ACA

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



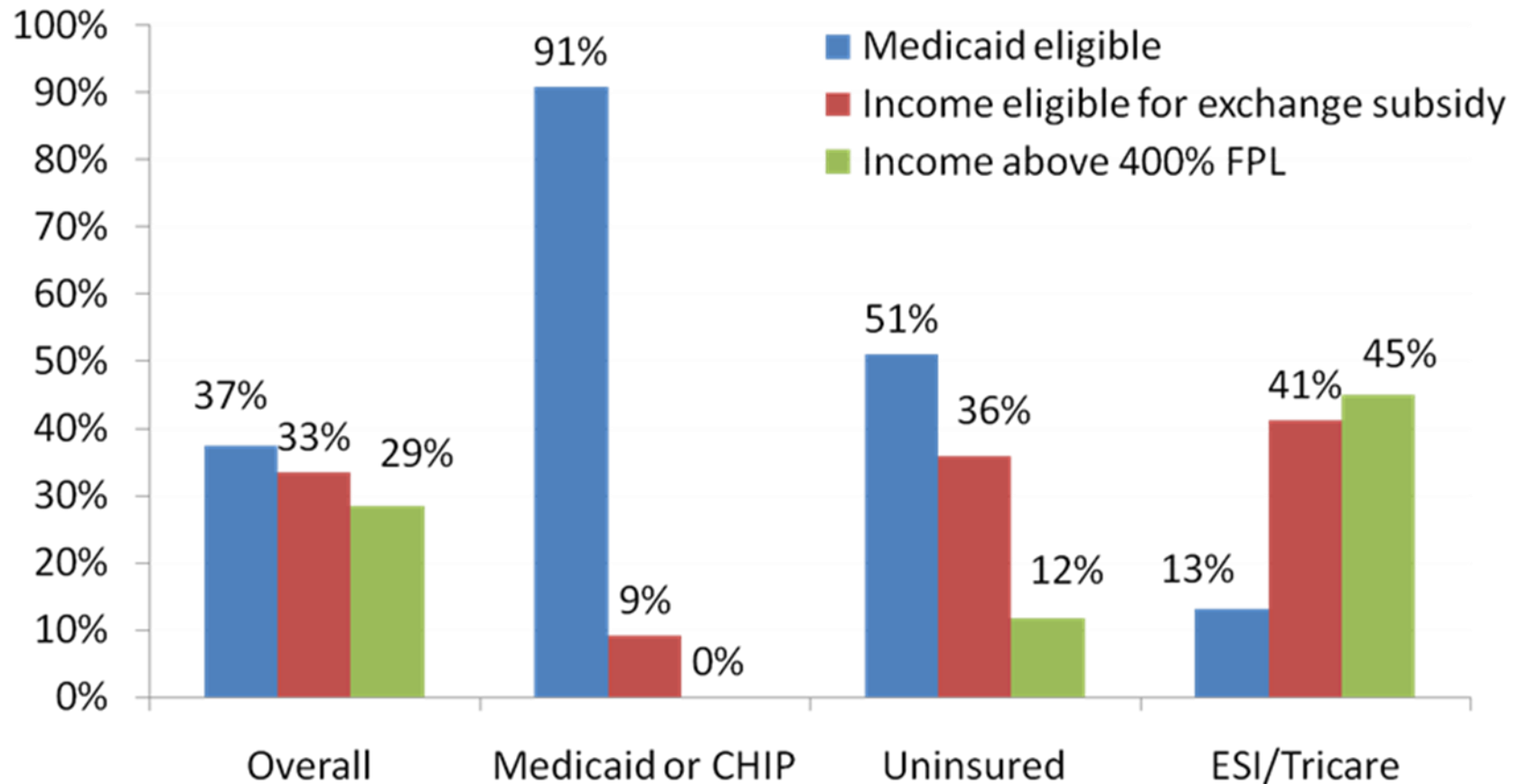
# Overall Conclusions

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- ❑ Limitations to the ACA provisions and anticipated barriers to the uptake of some provisions for survivors
- ❑ Both advocacy and education will likely be needed to assist survivors to access and utilize the new health care reform provisions



# Eligibility of Young Adult Cancer Survivors for Coverage under the Affordable Care Act (n=497)



Source: Analysis of 2008-2010 MEPS; Davidoff, Hill, Bernard, & Yabroff, unpublished.

Cohort: adults aged 18-39 reporting a cancer diagnosis ever.

Note: assumes that 100% of states implement Medicaid expansions. Eligibility for exchange subsidies also depends on whether person has an ESI offer that is affordable and adequate.

# Implications of the ACA

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- ❑ Improve access & affordability (e.g., state-run insurance, high-risk pool, Medicaid expansion, extended age of parental coverage)
  - Could increase numbers of CCS covered but may be financially prohibitive for some
- ❑ Improve security (e.g., no denial due to pre-existing conditions, no lifetime coverage limits)
  - Could allay fears of future coverage needs
- ❑ Improve continuity & preventive care (e.g., essential benefits for PCP visits, medical homes, required coverage for preventive services)
  - Proposed areas match with survivors' priorities but limitations in not survivor-specific

