Adolescent and Young Adult Health Outcomes and Patient Experience

AYA HOPE STUDY

AYA HOPE

AYA HOPE: A Population-based Cohort Study of Adolescent and Young Adults with Cancer

Linda Harlan, PhD, MPH, BSN

National Cancer Institute

Adolescent and Young Adult Health Outcomes and Patient Experience

AYA HOPE STUDY

Funded by:
National Cancer Institute with support from the LIVE**STRONG** Foundation

NCI Investigators:
Linda Harlan, Ashley Wilder Smith (Applied Research Program, Division of Cancer Control and Population Sciences)

SEER Principal Investigators:
Rosemary Cress (Greater California), Ann Hamilton (Los Angeles), Ikuko Kato (Detroit), Theresa Keegan (Northern California), Charles Lynch (Iowa), Stephen Schwartz (Seattle), Xiaocheng Wu (Louisiana)

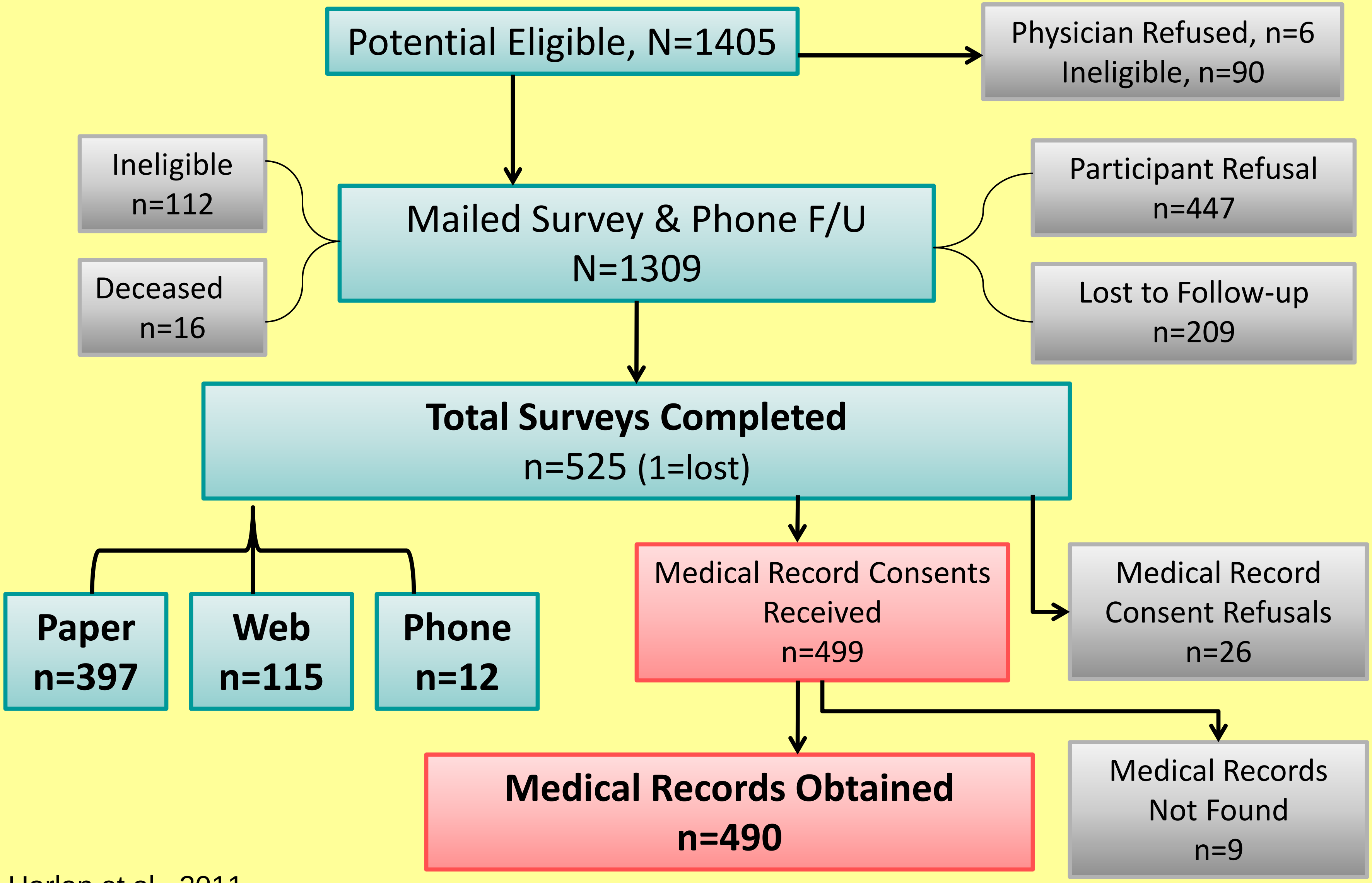
Study Objectives

- Feasibility study to obtain population-based data on:
  - **Patient/guardian consent**
  - **Medical records (hospitals and physician offices)**
  - **Patient survey (paper or web-based)**
- To address potential factors related to gaps in research, care, and outcomes for adolescent and young adult cancer patients
- Examines factors related to access to care, treatment and follow-up care, and the impact of cancer on physical and psychosocial functioning

Participants and Accrual

- 7 Surveillance Epidemiology and End Results (SEER) population-based cancer registries
- Eligible patients
    - Germ cell
    - ALL
    - HL
    - NHL
    - Sarcoma
- Diagnosed
    - Ages 15-39
    - Between July 1, 2007 - October 31, 2008
    - 6-14 months post-diagnosis
- Data collection August 2008 – October, 2009
- Follow-Up Survey 15-30 months post diagnosis

Recruitment



Potential Eligible, N=1405

Physician Refused, n=6
Ineligible, n=90

Ineligible
n=112

Deceased
n=16

Mailed Survey & Phone F/U
N=1309

Participant Refusal
n=447

Lost to Follow-up
n=209

Total Surveys Completed
n=525 (1=lost)

Paper
n=397

Web
n=115

Phone
n=12

Medical Record Consents Received
n=499

Medical Record Consent Refusals
n=26

Medical Records Obtained
n=490

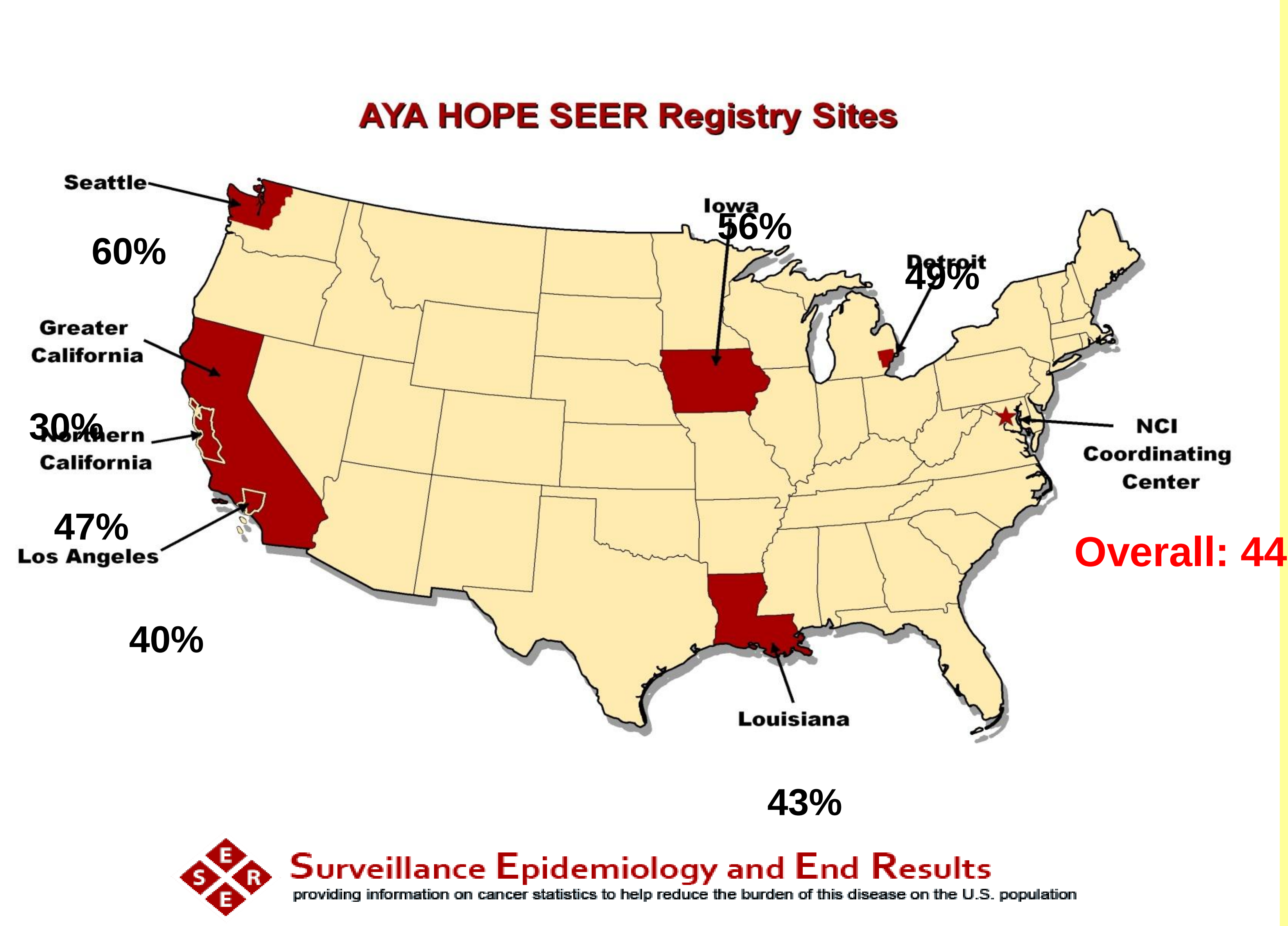
Medical Records Not Found
n=9

Harlan et al., 2011

Final sample

- 524 cancer patients, with:
    - **Germ cell (ovarian, testicular): n=205**
    - **Hodgkin lymphoma, n=142**
    - **Non-Hodgkin lymphoma, n=131**
    - **Acute lymphoblastic leukemia, n=21**
    - **Sarcoma (Ewing, osteosarcoma or rhabdomyosarcoma), n=25**

Response Rates at Recruitment Sites



60%

56%

49%

30%

47%

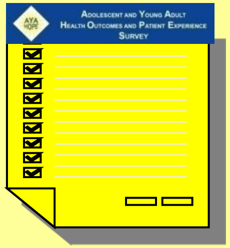
40%

43%

Overall: 44%

Harlan et al., 2011

Results Overview



Survey Data:

Sample Characteristics
Insurance Status
Participation in Clinical Trials
Quality of Life
Impact of Cancer
Information, Service Needs
Open-Ended Responses

Medical Record Data:

Insurance Status
Participation in Trials
Treated under a Protocol
Specific therapy given
Comorbidities
Type of Healthcare Facilities
Physicians' Subspecialties

Responders vs. Non-Responders

- Responders were more likely to be:
  - Non-Hispanic White
  - Female

- No differences by:
  - Age
  - Cancer site
  - Income
  - Education

Harlan et al., 2011

Sample Characteristics

Age, Gender, Race, n=524	
Age Group	
15-19	13%
20-24	18%
25-29	25%
30-34	22%
35-39	22%
Gender (Female)	37%
Race / Ethnicity	
White	63%
African American	8%
Asian/PI/AI/AN	10%
Hispanic	19%

Family & Education, n=524	
Marital Status	
Single	52%
Married/Partnered	42%
Divorced/Separated	6%
Live Alone	9%
Raising Children <18	40%
Education	
HS or less	28%
Some College	36%
College Grad	25%
Graduate School	10%
Comorbidity	28%

Quality of Life

Short Form-12 Health Survey

	Overall Physical (PCS)				**Overall Mental (MCS)**			
	AYA HOPE		**General US**		**AYA HOPE**		**General US**	
Age Group	*Mean*	*SD*	*Mean*	*SD*	*Mean*	*SD*	*Mean*	*SD*
18-24	**49.7***	(10.2)	53.0	(9.2)	46.8	(11.0)	46.0	(12.8)
25-34	**49.7***	(10.9)	53.3	(9.6)	**44.9***	(12.3)	48.9	(12.3)
35-44	50.0	(9.2)	52.0	(8.1)	**44.7***	(10.9)	48.8	(9.6)

AYA HOPE = age 34-42

Smith et al., 2013

Impact of Cancer On…

	Negative	None	Positive	N/A
Relationship with…				
… Mother	9%	24%	62%	5%
… Father	6%	28%	52%	14%
… Brothers, Sisters	5%	27%	61%	7%
… Spouse/partner, Boy/girlfriend	16%	12%	49%	22%
… Child/children	5%	12%	24%	58%
… Friends	12%	27%	57%	2%
Spirituality and religious beliefs	5%	33%	52%	10%
Plans for the future / goal setting	31%	20%	46%	3%

N/A = individuals could indicate “Does not apply”

Bellizzi et al., 2012

Impact of Cancer On…

	Negative	None	Positive	N/A
Financial situation	62%	26%	7%	4%
Body Image	59%	28%	10%	2%
Sexual function / intimate relations	48%	33%	4%	14%
Control over your life	47%	22%	29%	1%
Plans for having children	44%	24%	5%	26%
Plans for work	36%	33%	25%	5%
Confidence in your ability to take care of your health	34%	25%	40%	1%
Plans for education	18%	46%	18%	17%
Dating	18%	20%	4%	56%
Plans for getting married	11%	24%	8%	56%

N/A = individuals could indicate “Does not apply”

Bellizzi et al., 2011

Unmet Information and Service Needs

- 35% reported a need for a service that was not met
    - financial advice related to healthcare
    - mental health counselor
    - support group
  - Having any unmet service need was associated with worse HRQOL on multiple domains
  - Needing mental health services had the strongest associations with worse HRQOL outcomes
- >50% reported a unmet need for more information
  - non-white participants were more likely to report unmet information needs

Keegan et al., 2012; Smith et al., 2013

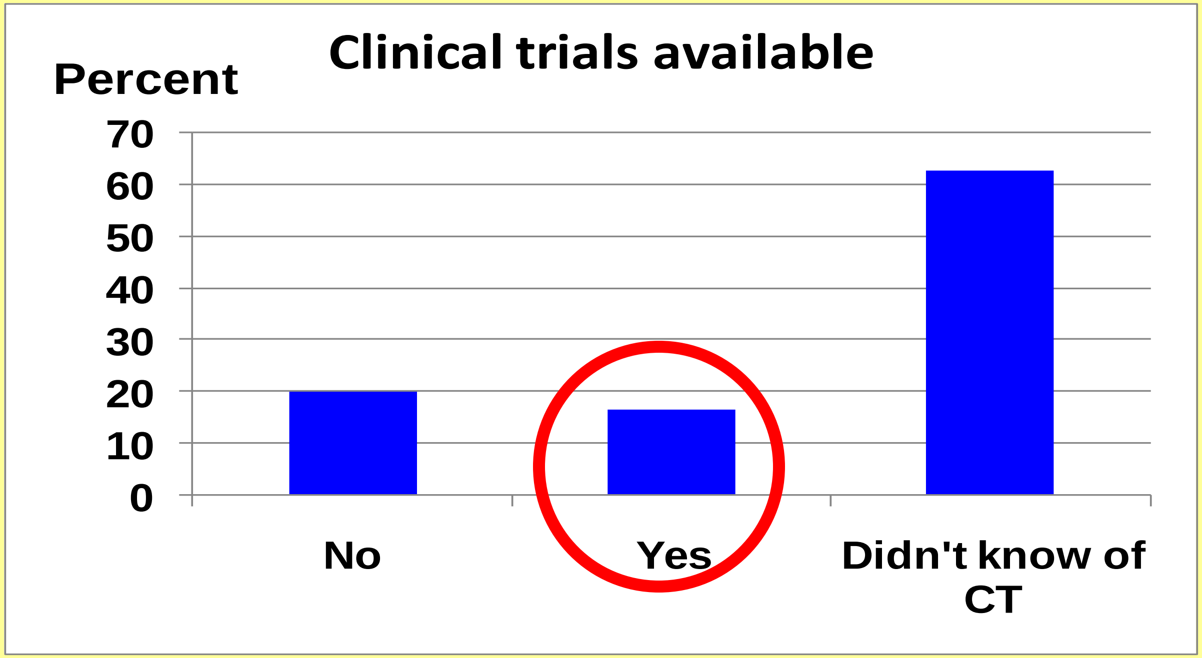
Social Information Needs

- Talking about cancer
  - Hispanics
  - Quality of Care
  - Number of symptoms
  - Support services needed – not received
- Meeting peer survivors
  - Age 20-29
  - Number of symptoms
  - Support services needed – not received

Kent et al., 2013

Clinical Trial Participation

Overall 7% participated in a clinical trial



- Top Reason AYAs gave for not joining a trial: “Worried that you might get treatment that had not been sufficiently tested”

Hospital/Physician

- Type of Healthcare facility*
  - Cancer Center: **45%**
  - Community hospital: **36%**
  - Academic Institution: **25%**
  - NCI cancer center: **18%**
  - Pediatric hospital: **2%**
  - Unknown: **1%**

- Physician Sub-specialty*
  - Medical Hem/Onc: **76%**
  - Surgery, General: **47%**
  - Medical: **40%**
  - Radiation Oncology: **31%**
  - Peds Hem/Onc/Med: **5%**
  - Other/Unknown: **5%**
  - Surgery, Orthopedic: **4%**

***Categories are not mutually exclusive**

Planned Analyses

- Initial treatment
- Clinical trials involvement
- AYA comorbidity
- Follow-up survey
  - Medical Care in AYA cancer survivors
  - Fertility preservation
  - Insurance in AYAs – health and life

Future Directions

- Research is needed to explore possible delays in diagnosis
- Better understanding of this population in long-term survivorship is needed
  - Specific needs related to access to medical records
  - Continuing/Follow-Up Care
  - ACA, Insurance coverage and financial problems

Publications

- Harlan LC, et al. Recruitment and follow-up of adolescent and young adult cancer survivors: the AYA HOPE Study. Journal of Cancer Survivorship, 2011, 5(3):305-14.
- Parsons HM, et al. The Impact of Cancer on Work and Education among Adolescent and Young Adult Cancer Survivors. Journal of Clinical Oncology, 2012, 30(19):2393-400.
- Bellizzi KM, et al. Positive and negative psychosocial impact of being diagnosed with cancer as an adolescent or young adult. Cancer, 2012, 118(20):5155-62.
- Keegan THM, et al. Unmet adolescent and young adult cancer survivors information and service needs: A population-based cancer registry study. Journal of Cancer Survivorship, 2012, 6(3):239-50.
- Smith AW, et al. Unmet support service needs and health-related quality of life among adolescent and young adults with cancer: the AYA HOPE Study. Frontiers in Pediatric Oncology, 2013, 3(75).
- Kent EE, et al. Talking about cancer and meeting peer survivors: social information needs in adolescents and young adults diagnosed with cancer. Journal of Adolescent and Young Adult Oncology 2013, 2(2):44-52.
- Smith AW, et al. Health-related quality of life of adolescent and young adult cancer patients in the United States: the AYA HOPE Study. Journal of Clinical Oncology, 2013;31(17):2136-45.
- Zebrack B, et al. Cancer sucks, and other ponderings by adolescent and young adult cancer survivors. Journal of Psychosocial Oncology (in press)

AYA HOPE Study Group

Fred Hutchinson Cancer Research Center (Seattle, WA): Stephen M. Schwartz, Ph.D. (P.I.); Martha Shellenberger; Tiffany Janes

University of Iowa (Iowa City, IA): Charles F. Lynch, M.D., Ph.D. (P.I.); Michele M. West, Ph.D.; Lori A. Somers, R.N.

Wayne State University (Detroit, MI): Ikuko Kato, M.D., Ph.D (P.I.); Ann Bankowski; Marjorie Stock

California Cancer Registry/Public Health Institute (Sacramento, CA): Rosemary Cress, DrPH (P.I.); Gretchen Agha; Mark Cruz

Louisiana State University (New Orleans, LA): Xiao-cheng Wu, M.D., MPH (P.I.); Vivien Chen, PhD.; Pinki K. Prasad, M.D.

Cancer Prevention Institute of California (Fremont, CA): Theresa Keegan, Ph.D (P.I.); Laura Allen; Zinnia Loya; Lisa Shelton-Herendeen

University of Southern California (Los Angeles, CA): Ann Hamilton, Ph.D (P.I.); Jennifer Zelaya; Urduja Trinidad

National Cancer Institute (Bethesda, MD): Linda C. Harlan, BSN, MPH, Ph.D.; (Investigator) Ashley Wilder Smith, Ph.D, MPH (Co-investigator); Gretchen Keel,BS,BA; Jana Eisenstein, MS.

Consultants: Arnold Potosky, PhD.; Keith Bellizzi, Ph.D.;Karen Albritton, MD, Michael Link, MD; Debra Friedman, MD; Brad Zebrack, Ph.D.

For More Information

http://outcomes.cancer.gov/surveys/aya/

Applied Research Program
Division of Cancer Control and Population Sciences
National Cancer Institute
Room 3E426
9609 Medical Center Drive, MSC 9762
Bethesda, Maryland 20892-9762