



***A Model For Big Science For The
21st Century
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Love/Avon Army of Women

A New Model for Partnering Women and Scientists to Find the Cause and Prevention of Breast Cancer

- Overview of the concept
- Success of the idea to date
 - Women
 - Researchers
- Current challenges
- Proposal for future development

Goals of the Army of Women

- Encourage **women** to take the next step in breast cancer advocacy and participate in research.
- Educate **women** about the research process.
- Get **women** invested in the concept of research to find the answers.
- Forge a partnership between **women** and **researchers** to end breast cancer.

Goals of the Army of Women

- Increase the amount of **research** focused on the cause and prevention of breast cancer.
- Shift **research** from animal models to women when possible.
- Accelerate **research** by accessing a pool of ready volunteers of all ages, ethnicity, with or without breast cancer.
- Encourage **researchers** to study clinically important questions.

Army of Women Collaborators

- *American Association of Cancer Researchers:* representing the scientific community.
- *National Breast Cancer Coalition:* representing the women who participate.

What is the Army of Women (AOW)?



A pool of healthy women (normal, high risk, survivors) who are willing to participate in breast cancer research

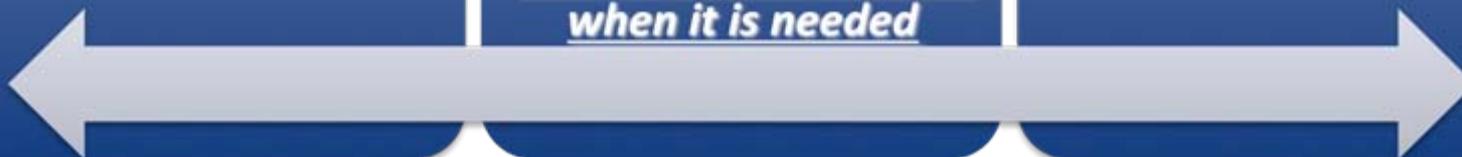


A “just in time” resource for basic scientists and epidemiologists who need human tissues, fluids and/or information for breast cancer research

**Exactly what is needed
when it is needed**



An independent non-profit service to match the two



How it Works

Army of Women Members

-Women sign up online agreeing to consider participation in research studies

-Minimal information is collected in advance

- Approved studies are periodically sent to the whole Army of Women describing a particular study, eligibility criteria, and requirements

-If they fit the eligibility criteria and want to take part, they RSVP on www.armyofwomen.org where they undergo a secondary screen

 **army of women**
LOVE/AVON Going Beyond a Cure

[Join the Army](#) [Volunteer Sign-in](#) [Researcher Sign-in](#)

[Contact Us](#) | [Site Map](#) |



ONE MILLION WOMEN. RESEARCH GOAL. REVOLUTIONARY OPPORTUNITY.
Together we can prevent breast cancer.



TAKE ACTION NOW.
JOIN THE ARMY OF WOMEN.
Dr. Susan Love

[About Us](#) [Get Involved](#) [Volunteer Login](#) [For Researchers](#) [Army Town Hall](#) [News & Events](#)

[Invite a Friend](#) [Spread The Word](#) Font Size: [T](#) [T](#) [T](#)

OUR GOAL OF RECRUITING ONE MILLION WOMEN STARTS WITH ONE — YOU.

Volunteers in the Army of Women as of 07/19/09

0 2 9 6 1 7 2

JOIN THE MOVEMENT TO GO BEYOND A CURE!

The Love/Avon Army of Women offers a revolutionary new opportunity for YOU to partner with research scientists to move us beyond a cure.

Breast cancer has been around for decades, but it does not have to be our future. We can be the generation that eliminates breast cancer by identifying what causes this disease and stopping it before it starts. Sign up for your sister, mother, daughter, granddaughter, best friend, and the woman you met last week.

Help us eradicate breast cancer once and for all. Join the Army of Women today!

[SIGN UP TODAY!](#)

FOLLOW AND CONNECT WITH US

Join us on [Facebook](#), add the [Army of Women Widget](#) to your webpage or social networking site, and help us spread the word about the Army of Women! Want more? Follow us everyday on [Twitter!](#)

Be the one to help us reach one million women strong.

<p>In the Blog</p>  <p>June 11, 2009 The Today Show May 29, 2009 Reese Witherspoon Joins Our Army</p> <p>Read All Army of Women Blogs</p>	<p>Support Our Cause</p>  <p>Wear your support! Purchase the Beyond a Cure pendant. For just \$5, you can show your support for the Army of Women and the movement to go beyond a cure.</p> <p>Purchase your Beyond a Cure pendant today!</p>	<p>Affiliates & Ambassadors</p>  <p>Be part of the team that is changing the future of breast cancer research! Have your group become an ACOW Affiliate or Ambassador today!</p> <p>Become an Affiliate or an Ambassador</p>	<p>For Researchers</p>  <p>The Army of Women has established key relationships with the American Association for Cancer Research (AACR) and the National Breast Cancer Coalition.</p> <p>Learn more and submit your research proposal</p>
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AVON Foundation for Women | DR. SUSAN LOVE RESEARCH FOUNDATION

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built@zoo-media

How It Works

Scientist

Register

Scientists register at www.armyofwomen.org website for access to the current membership base of 300,000 women for recruitment for their basic science and epidemiologic studies

How it Works

Partnership Between Women and Researchers

- Researchers are responsible for explaining the research to the participants as well as communicating the aggregate results of the study at the end:
 - In person if they are conducting the study themselves.
 - Through an AOW webinar if we are collecting samples and shipping to them.

Army of Women

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Army of Women

Launch: October 2008

- Today Show, NBC Nightly News, ABC World News, the View, Good Morning America.
- AARP Prime Time Radio, Bulletin.
- Oprah Magazine, Women's Health, Real Simple and many more.

300,000 women have signed up!

Army of Women

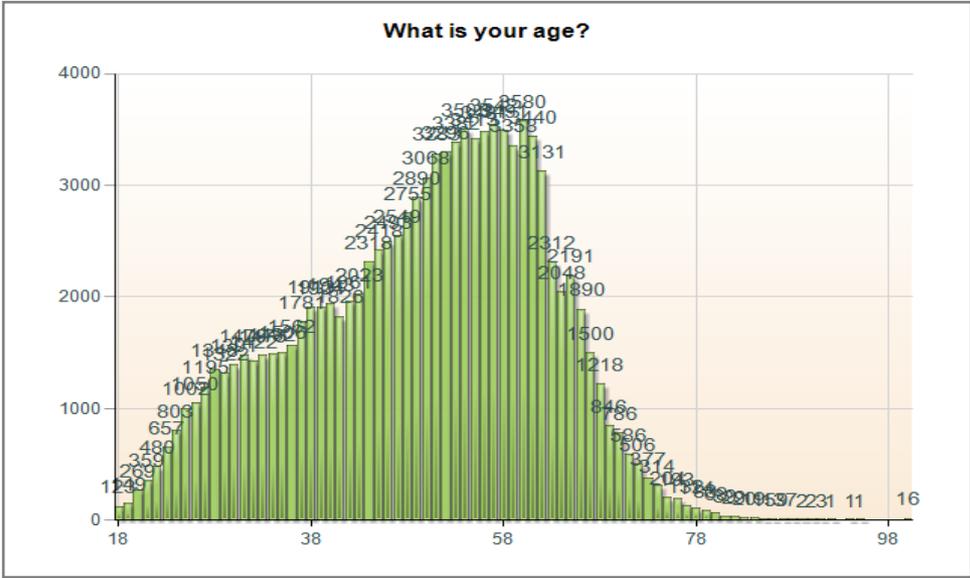
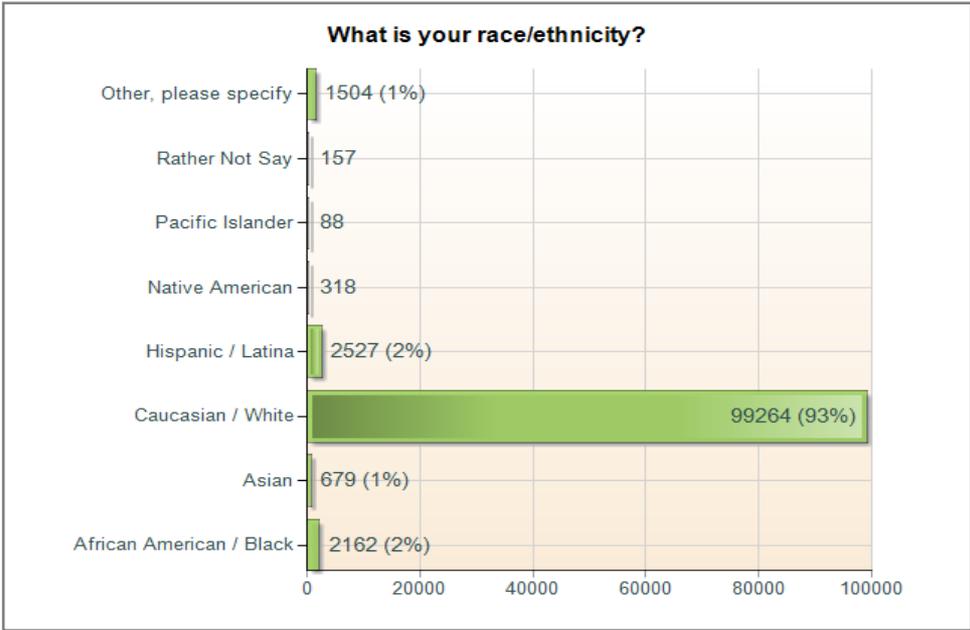
Who are they?

In December 2008, The Army of Women surveyed all of its members in order to develop a snapshot of their demographic and breast cancer history:

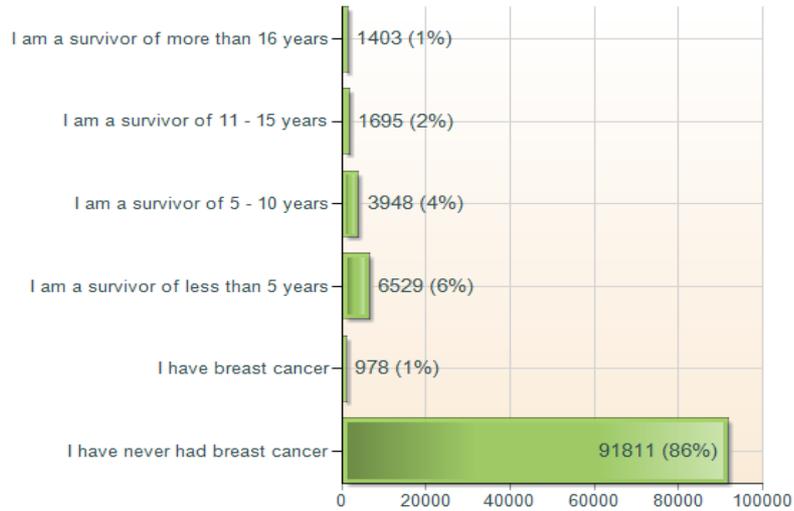
- **107,638 women responded and completed to the survey within 72 hours**

Who is in the Love/Avon Army of Women?

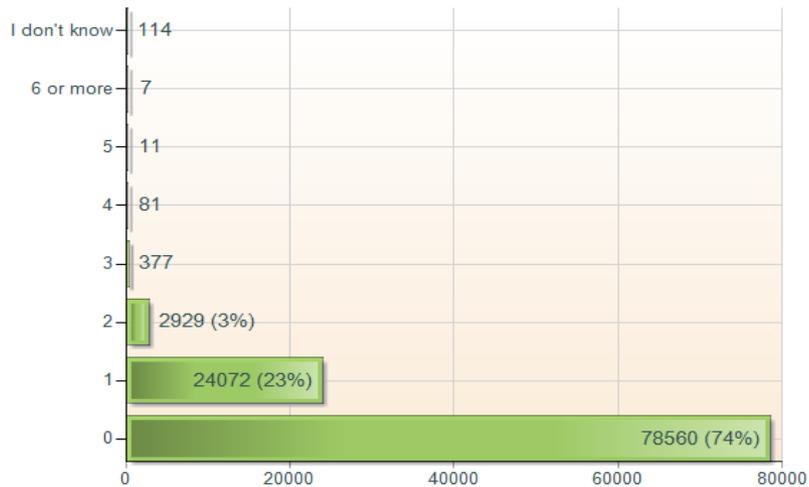
- **Ages 18-100**
- **All ethnicities**
- **Representation from every state**
- **Women with a range of risk factors**
- **“Healthy” women and Survivors**



Choose the answer that best describes your breast cancer history



How many of your FIRST DEGREE relatives have had breast cancer? First degree relatives include: mother, father, brother, sister, and your children.



As of June 2009

- Ten studies have been launched.
- Over 11,000 women have qualified to participate in studies.

Army of Women National Research Studies

- NIH/NIEH Funded Sister Study: A national study that began in 2002 to study how environment and genes affect breast cancer risk. The researchers partnered with the AOW to recruit the final *5,000 women* needed to close the study:
 - **National Study**
 - **Launched 10/23/08, closed 3/30/09**
 - **52,411 total responses from the AOW**
 - **In 48 hours: 1600 qualified and recruited**
 - **In two weeks 2300 qualified and recruited**
 - **5000 total recruited**

Army of Women

National Research Studies

- Avon Foundation for Women Funded Milk Study: Biomarker study at University of Massachusetts recruiting lactating women scheduled for a breast biopsy. The researchers partnered with the AOW to recruit *250 women*:
 - **National Study**
 - **Launched 11/17/2008**
 - **62,826 total responses from the AOW**
 - **In 24 hours: 31 qualified and recruited (representing a 6 month acceleration of recruitment)**
 - **To Date: 214 recruited**

Army of Women

Local Research Studies

- NIH funded Cognitive and Emotional Effects of Breast Cancer study at Stanford University: A study using imaging, genetic markers, and neuropsychological testing to define the cognitive deficits associated with breast cancer and chemotherapy. The researcher partnered with the AOW to recruit *180 women*:
 - **Local Study (San Francisco)**
 - **Launched 4/16/2009, closed 5/4/09**
 - **Need 180 subjects**
 - **16,446 total responses from the AOW**
 - **1,314 qualified and recruited**

Army of Women

National Research Studies

- A study from the University Of Ottawa, A Web-Based Survey of Psychosocial Issues in Women Diagnosed with Breast Cancer: An online survey to study how breast cancer affects psychosocial and parenting measures. The researcher partnered with the AOW to recruit *1000 women*:
 - **National Study**
 - **Launched 4/30/09, closed 5/1/09: Closed > 24 hours**
 - **15,534 total responses from the AOW**
 - **5,830 qualified and recruited**

Army of Women

National Research Studies

- An NIH-funded study, Variations in Health Needs of Breast Cancer Survivors at Boston University: Quality of Life study to reduce the disparity in cancer burden due to sexual orientation . The researcher partnered with the AOW to recruit *100 women* who are lesbian, bisexual, or partner with other women:
 - **National Study**
 - **Launched 6/10/09**
 - **15,412 total responses from the AOW**
 - **158 qualified and recruited**

Army of Women:

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- **Current challenges**
- Proposal for future development

Army of Women

Challenges: Women

- AOW members complain about the lack of studies which they are eligible for.
- Challenge in recruitment of minorities- AOW should represent the US population
- Website design that limits abilities
 - Expand social networking
 - Translate into Spanish
 - Accommodate the techno-challenged

Army of Women

Challenges: Scientific Community

- Identifying funded peer reviewed studies that could benefit from using the AOW to complete recruitment:
- Convincing scientists and epidemiologists to consider using human tissues and fluids:
- Encouraging grant proposals utilizing the AOW:

Army of Women:

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- Current challenges
- **Next Step**

A Model For Big Science For The 21st Century Powered by caBIG®

Empower women (the public) to be part of and feel invested in breast cancer research:

- By educating women in the research process
- By including women in the collection and maintenance of data
- Through engaging women in figuring out the key clinical questions of the day
- Through the first large internet based cohort

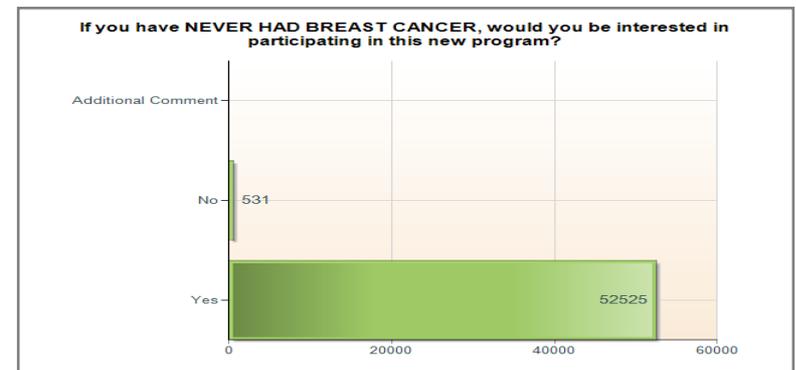
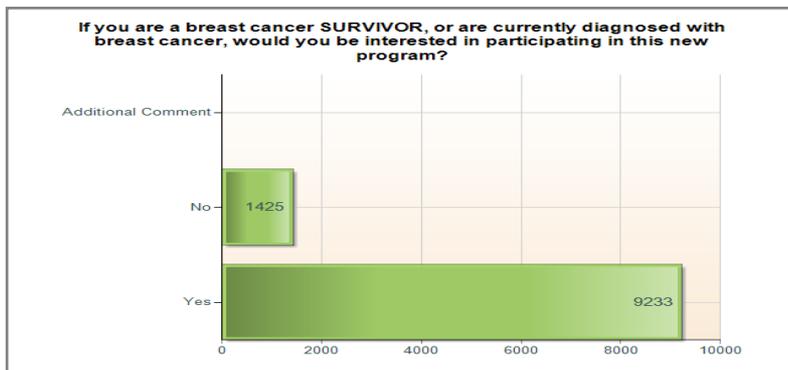
The Health of Women (HOW) Study

Health of Women Study

- Invite all women in the AOW to join:
 - Filling out periodic modules that address different topics and are password protected and individually controlled
 - Aggregate data available to AOW and approved researchers.
 - Code held securely by the AOW
 - Application created by caBIG[®]
 - Application flexibility and user consent for AOW to do follow up

Is Recruitment To Such a Hybrid Cohort Feasible?

- AOW Members were surveyed as to their willingness to participate
 - Total response 77,719/272,000 (29%)
 - Survivors: 87% yes
 - Healthy women: 99% yes



caBIG[®] Powered Online Platform Allows Us To Do Cohort Studies Differently

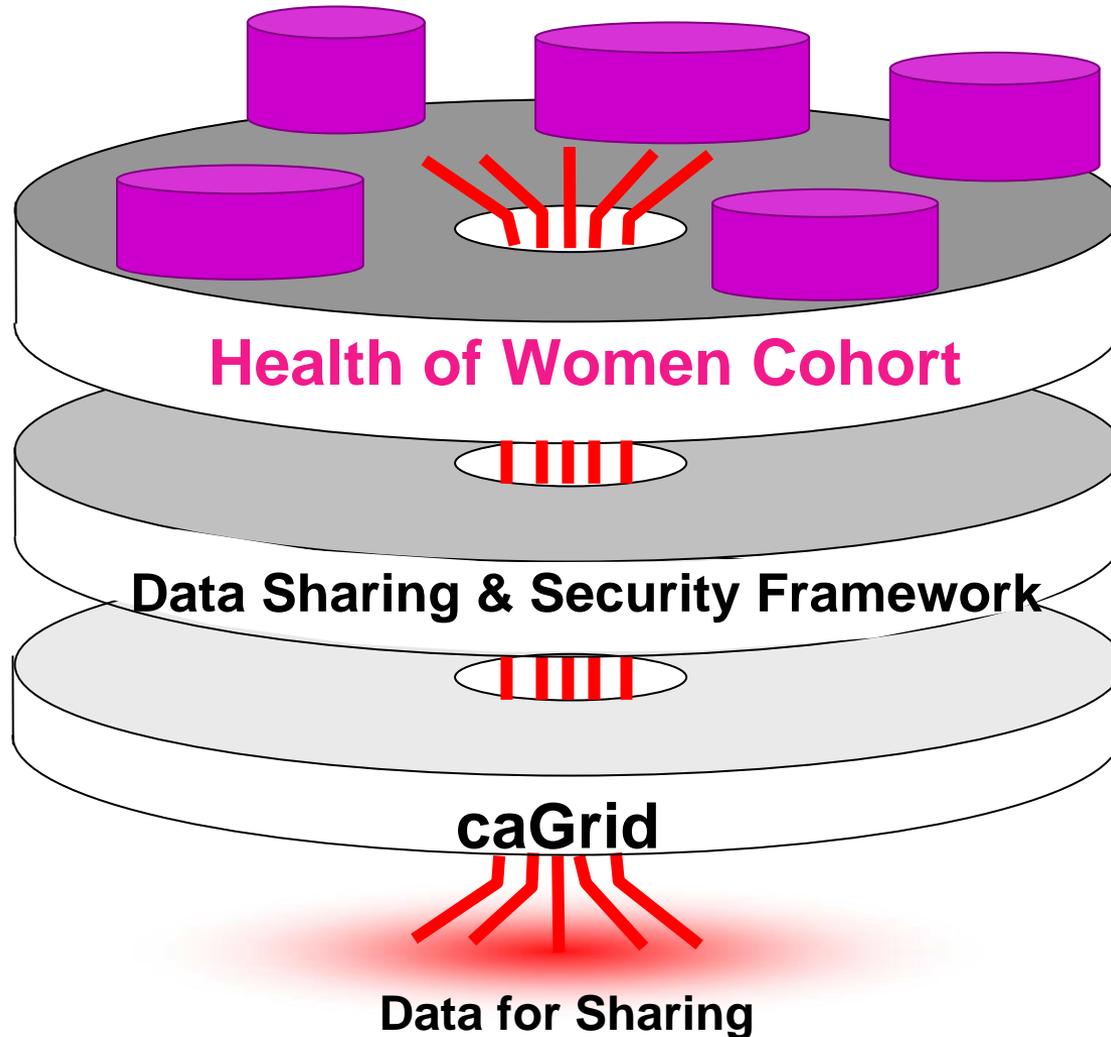
- Periodic question modules covering specific topics rather than one long questionnaire:
 - Questions remain current
 - Popular/ member generated questions can be added
- Data cleaning and management made easy:
 - Skip patterns will help prevent common mistakes
 - Drop down menus
 - Instant access to data

caBIG[®] Powered Online Platform Allows Us To Do Cohort Studies Differently

- Subcohorts can be designated on the back end:
 - Male breast cancer
 - Healthy women
 - Survivors
 - Women living with breast cancer
 - Women with metastatic disease
 - Lesbians
- Rolling admission
 - Cohorts designated at back end to take into consideration cohort effects

Exploit Full Power Of Informatics

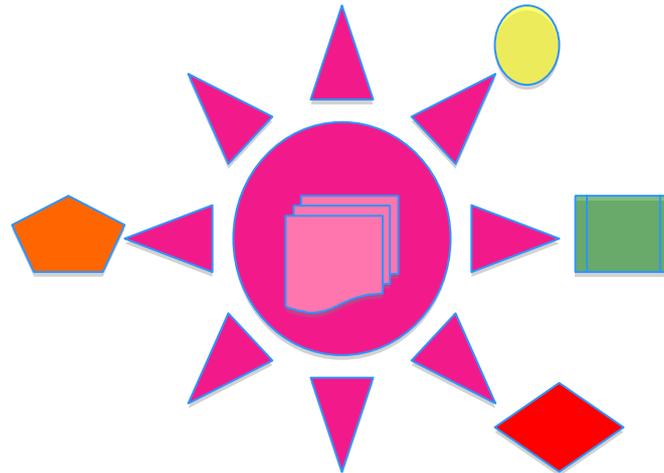
Developed By caBIG[®]



- Facilitate data sharing while maintaining security and privacy.
- Develop a “wikipedia” model for the enhancement of the database as new studies are completed.

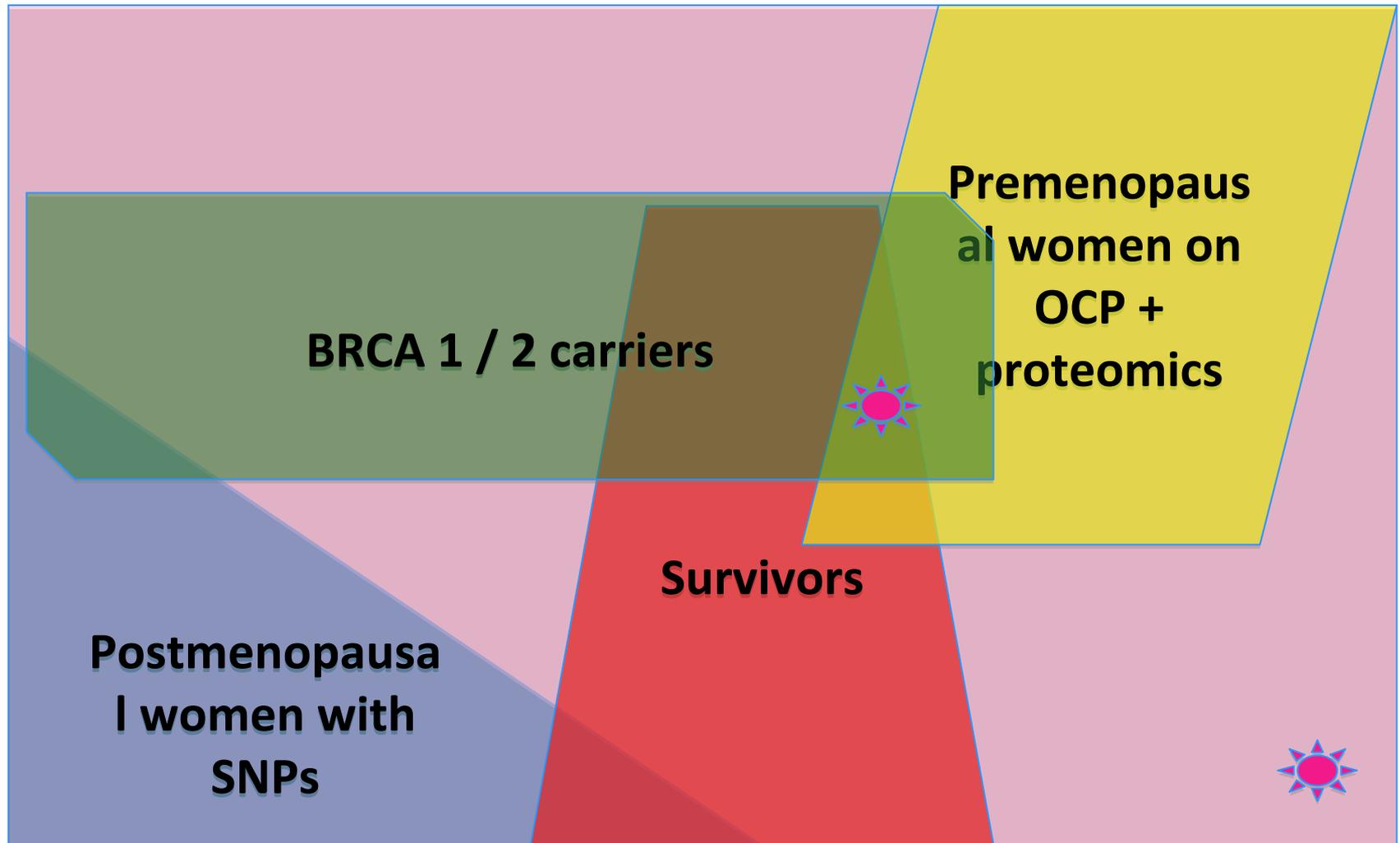
Health of Women Study

- Woman fills out the module of her choice for HOW.
- Researchers use HOW Grid to access database for hypothesis driving research.
- Researchers submit questions for a particular module and are given data.
- Biologic samples are requested for subgroups and data is shared back with the AOW and attached to the original record through the code as an addendum to their record.



Health of Women Study

A model of data sharing



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- Proposal for future development
 - Basic Concept of Health of Women Study
 - CaBIG Technology
 - **Online Application**

HOW Study: Longitudinal Cohort

- Partnership with Leslie Bernstein and Katherine Henderson at City of Hope
- Series of modules addressing different topics
 - Your health
 - Family history
 - Nutrition
 - Physical Activity
- Questions proposed by members of the AOW
- Timely issues

HOW Module 1

- Based on the user experience and answers, an automated skip pattern will allow user to fill out only relevant information based on health history.
- Both men and women can be part of HOW, and the gender question will determine skip pattern and questions.
- Both breast cancer survivors and healthy women can be part of HOW, and the breast cancer history question will determine the skip patterns and questions.

HOW Module 1

Create Account



Navigation: [About Us](#) | [About HOW](#) | [Using this Website](#) | [Privacy Policy](#) | [Join HOW](#) | [My Account](#)

Secondary Navigation: [My Account](#) | [Contact Us](#) | [Army of Women](#) | [Review Consent](#)

 **The Health of Women Study (HOW)**

Create Account

Create User Name:
(at least 6 characters, including letters and or numbers)

Select Password:
(at least 6 characters, including letters and or numbers)

Confirm Password:

Password Hint:

Security Question: ▼

Security Answer:

[Register](#)

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HOW Module

Data Security and Consent

- Data Security and Consent
 - They have to be a member of the AOW
 - Separate log in for the cohort with more stringent security and encryption
- Consent given online after reading information sheet:
 - Can be withdrawn at any time through My Account
 - Consent to the use of identifiable data by the cohort team
 - Consent to long term follow up

HOW Module 1

Consent Form

[About Us](#)[About HOW](#)[Using this Website](#)[Privacy Policy](#)[Join HOW](#)[My Account](#)[My Account](#) | [Contact Us](#) | [Army of Women](#)

The Health of Women Study (HOW)

Consent Form

Research Study Information Sheet

The Health of Women Study (HOW) of the Love/Avon Army of Women

Background

With 1 in 8 women expected to develop breast cancer in their lifetime, breast cancer is the most common cancer among women in the United States. On January 1, 2006, in the United States there were approximately 2,533,193 women alive who had a history of breast cancer. No one knows the exact causes of breast cancer. Doctors often cannot explain why one woman develops breast cancer and another does not.

Purpose of the Study

This study seeks to collect health-related information over a period of time to answer questions that researchers and the general public have regarding the cause and prevention of breast cancer.

What will Happen During the Study?

You will be one of approximately one million Love/Avon Army of Women members asked to participate in the study. You will be provided access to a series of on-line surveys called "modules". Each module will ask a different set of questions related to medical history, reproductive health history, diet and exercise, and other areas of health and well-being.

Agreeing to Participate

HOW Module 1

About Me

Navigation: [About Us](#) | [About HOW](#) | [Using this Website](#) | [Privacy Policy](#) | [Join HOW](#) | [My Account](#)

Secondary Navigation: [My Account](#) | [Contact Us](#) | [Army of Women](#) | [Review Consent](#)

Logo: army of women
LOVE/AVON Going Beyond a Cure

The Health of Women Study (HOW)

Module 1 | Module 2 | Module 3

Navigation: [About Me](#) | [My Reproductive Health](#) | [My Health History](#) | [My Health as of Today](#) | [My Breast Cancer](#) | [My Treatment](#)

- Enter your Health History
 - About Me**
 - My Reproductive Health
 - My Health History
 - My Health as of Today
 - My Breast Cancer
 - My Treatment
- Review your Health History

About Me

Last Name:

First Name:

Middle Initial:

Street Address:

City:

State:

Zip:

Phone Number:

Email Address:

Fax Number (optional):

Date of Birth:

Sex: Female Male

Check the box that best describes your *highest* level of completed schooling:

K-8

Vocational school

...

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HOW Module 1

My Reproductive Health

About Us | About HOW | Using this Website | Privacy Policy | Join HOW | My Account

My Account | Contact Us | Army of Women | Review Consent

My Health of Women Study (HOW)

Module 1 | Module 2 | Module 3

About Me | **My Reproductive Health** | My Health History | My Health as of Today | My Breast Cancer | My Treatment

- Enter your Health History
 - About Me
 - My Reproductive Health**
 - My Health History
 - My Health as of Today
 - My Breast Cancer
 - My Treatment
- Review your Health History

My Reproductive Health

Tell us about your reproductive history:

How old were you when you had your first menstrual period?

- I have never had a period
- Under age 10
- 10
- 11
- 12
- 13
- 14
- 15
- 16
- 17+
- I don't know / I can't remember

Have you ever taken birth control pills (oral contraceptives) for one month or longer?

- No
- Yes, I used birth control pills in the past

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HOW Module 1

My Health History

Navigation: [About Us](#) | [About HOW](#) | [Using this Website](#) | [Privacy Policy](#) | [Join HOW](#) | [My Account](#)

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LOVE/AVON Going Beyond a Cure

The Health of Women Study (HOW)

Module Selection: **Module 1** | Module 2 | Module 3

Section Navigation: [About Me](#) | [My Reproductive Health](#) | **My Health History** | [My Health as of Today](#) | [My Breast Cancer](#) | [My Treatment](#)

- Enter your Health History
 - ✓ About Me
 - ✓ My Reproductive Health
 - **My Health History**
 - My Health as of Today
 - My Breast Cancer
 - My Treatment
- Review your Health History

My Health History

Have you ever been told by a health professional that you have any of the following conditions?

Another cancer (other than breast cancer) or leukemia?

No

Yes

Type of cancer

Date of diagnosis (mm/yyyy)

Arthritis, rheumatism, or other connective tissue disorder

No

Yes

Type

Age at onset

Glaucoma

No

Yes

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HOW Module 1

My Breast Cancer

About Us | About HOW | Using this Website | Privacy Policy | Join H... | My Account

My Account | Contact Us | Army of Women | Review Consent

The Health of Women Study (HOW)

Module 1 | Module 2 | Module 3

About Me | My Reproductive Health | My Health History | My Health as of Today | **My Breast Cancer** | My Treatment

- Enter your Health History
 - ✓ About Me
 - ✓ My Reproductive Health
 - ✓ My Health History
 - ✓ My Health as of Today
 - **My Breast Cancer**
 - My Treatment
- Review your Health History

My Breast Cancer

Have you ever had breast cancer?

Yes

No

I don't know/I'm not sure

In what year were you first diagnosed with cancer?

I don't know/I'm not sure

What was the stage of your cancer at your diagnosis? [LEARN MORE](#)

In Situ (DCIS)

Stage I-III

Stage IV (metastatic disease)

I don't know/I'm not sure

How did your physician describe your cancer at diagnosis (check all that apply)? [LEARN MORE](#)

In situ (DCIS)

In situ (LCIS)

Ductal carcinoma (invasive or infiltrating)

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HOW Module 1

My Treatment

Navigation: About Us | About HOW | Using this Website | Privacy Policy | Join HOW | My Account | Account

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The Health of Women Study (HOW)

Module 1 | Module 2 | Module 3

About Me | My Reproductive Health | My Health History | My Health as of Today | My Breast Cancer | **My Treatment**

- Enter your Health History
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 - My Health History
 - My Health as of Today
 - My Breast Cancer
 - My Treatment**
- Review your Health History

My Treatment

Have you ever had any of the following?

...surgery for breast cancer or prevention?

Yes No [\[Learn More\]](#)

Select all sites of past surgery:

Left breast

- Left breast lumpectomy / partial mastectomy
Year (YYYY): Month (if within the past 12 months):
- Left breast re-excision
- Left breast excisional biopsy
- Left breast mastectomy for diagnosed breast cancer (therapeutic)
- Left breast mastectomy for prevention (prophylactic)
- Left breast sentinel lymph node biopsy

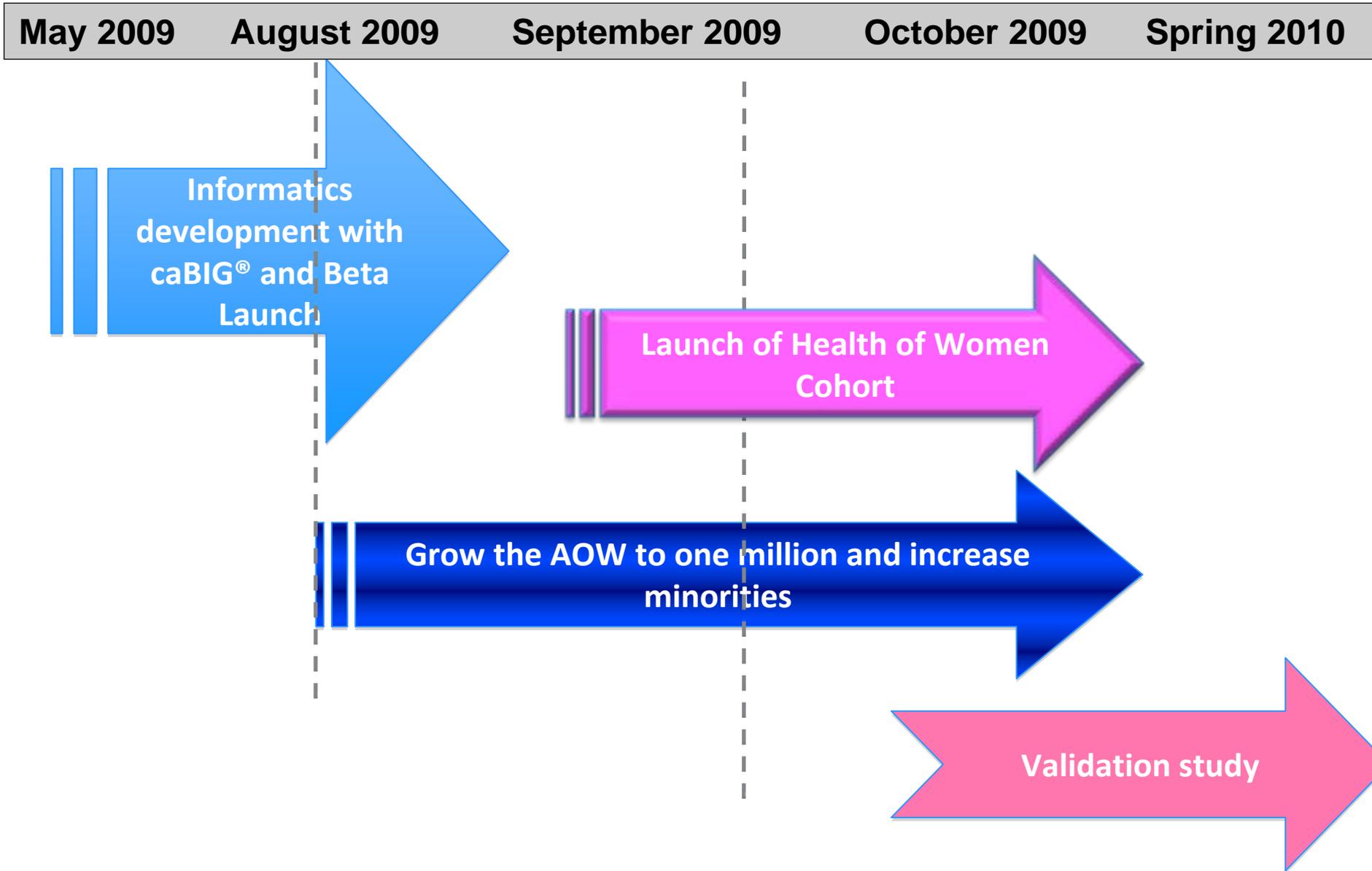
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Health of Women Study: Timeline

- **August 2009:** Focus group testing (1000)
 - Test the informatics for bugs and ease of use
 - Test the questions for understanding
 - Determine ideal time/length of one module
- **September 2009:** Invite the current 300,000 AOW members join HOW Study
 - Phased launch
- **October 2009:** Officially launch cohort
 - National media campaign
 - Test data aggregation
 - Validate information in subset of women

HOW Timeline



May 2009

August 2009

September 2009

October 2009

Spring 2010

Informatics
development with
caBIG® and Beta
Launch

Launch of Health of Women
Cohort

Grow the AOW to one million and increase
minorities

Validation study

Moving Beyond The Cure!

The Love/Avon Army of Women needs YOU!

- **Register yourself**
- **Encourage your family, friends and patients to register**
- **Spread the word to researchers**
- **Submit your studies/questions**

www.armyofwomen.org

and...

Coming Soon

A collaboration of the Dr. Susan
Love Research Foundation and
caBIG[®]

Health of Women Study

Love/Avon Army of Women