Educating about breast and ovarian cancer risk.
Facilitating patient/physician communication.
Saving lives.

Galen Cole, PhD, DAPA, MPH, LPC
Associate Director for Communication
Division of Cancer Prevention and Control

CDC HealthCommWorks.com

Tools Under Development

MessageWorks

Crafting and Defending Effective Messages

SocialWorks

Strategizing Social Media

ProofWorks

Evaluating Communication

U.S. Department of Health and Human Services
Centers for Disease Control and Prevention

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CUSTOMIZE

ADAPTABLE INTERFACE

SARAH'S STORY

National Center for Chronic Disease Prevention and Health Promotion
Division of Cancer Prevention and Control

Educating about breast and ovarian cancer risk.
Facilitating patient/physician communication.
Saving lives.

Doug George
BodyTalk Project Lead / Senior Web Designer – ORISE

Presentation
9/22/2011

National Center for Chronic Disease Prevention and Health Promotion
Division of Cancer Prevention and Control

Body TALK

Mission

The Division of Cancer Prevention and Control (DCPC) wanted to create a decision support tool that will:

- Educate young women, and their physicians, about genetic and lifestyle risk factors for breast and ovarian cancers.
- Help improve communication between young women and their physicians.
- Place special emphasis on reaching out to 18-44 year-old women who are at risk for, or have been diagnosed with, breast cancer.
- Integrate easily with a physician's existing workflow

Mission

BodyTalk will:

The Division of Cancer Prevention and Control (DCPC) wanted to create a decision support tool that will be:

- Easily scalable in a real-world environment
- Deployed on the Web as well as on iPhone and Android smartphone platforms
- Based on a similar tool developed for the Agency for Healthcare Research and Quality (AHRQ) called "Cancer in the Family".

Mission

BodyTalk will:

Promote key components of The Early Act (http://wassermanschultz.house.gov/earlyact), which encourages young women to:

LEARN the facts

KNOW their bodies

SPEAK UP for their health

EMBRACE support

Body TALK

Mission

BodyTalk will:

Educate patients, and their physicians, about the nature and importance of:

- Lifestyle and familial risk factors for breast and ovarian cancer
- Risk reduction strategies and evidence-based healthy lifestyles to reduce disease onset, metastasis or recurrence
- Early detection and early warning signs for breast cancer
- Screening, including genetic counseling where appropriate

Body TALK

Mission

BodyTalk will:

- Educate young women about their individual risk for carrying the BRCA1 and BRCA2 genetic mutation
  - System leverages personal and familial cancer histories, age, ethnicity, and gender
- Educate young women about their general cancer risk based on lifestyle-based cancer risk factors.
  - Diet
  - Exercise
  - Body Mass Index
  - Alcohol Consumption
  - Tobacco Use

Body TALK

Mission

BodyTalk will:

- Facilitate communication between a young woman and her physician on the subject of breast and ovarian cancer risk.
- Allows data sharing between patient and physician
- Patients get detailed risk profile, complete with tips for talking with their physician
- Physicians can also get access to their patient's risk profile, complete with reported family history and tips for talking with their patients

Mission

BodyTalk is:

- Secure
  - HIPAA-compliant database is encrypted and protected against unauthorized access.
  - The patient is in control of her own data at all times – sharing functionality is not automatic.
- Synchronous
  - Data entered into either the smartphone app or the website is immediately mirrored on the other platform.

Body TALK

Mission

BodyTalk is:

- Social
  - Links to educational information or support resources may be shared via social media, e.g. Facebook and Twitter.
- Scalable
  - No central system administration is necessary for clinics and patients to participate.
  - Utilizes a content management system to store and/or generate website content.

How BodyTalk Works (30,000ft. View)

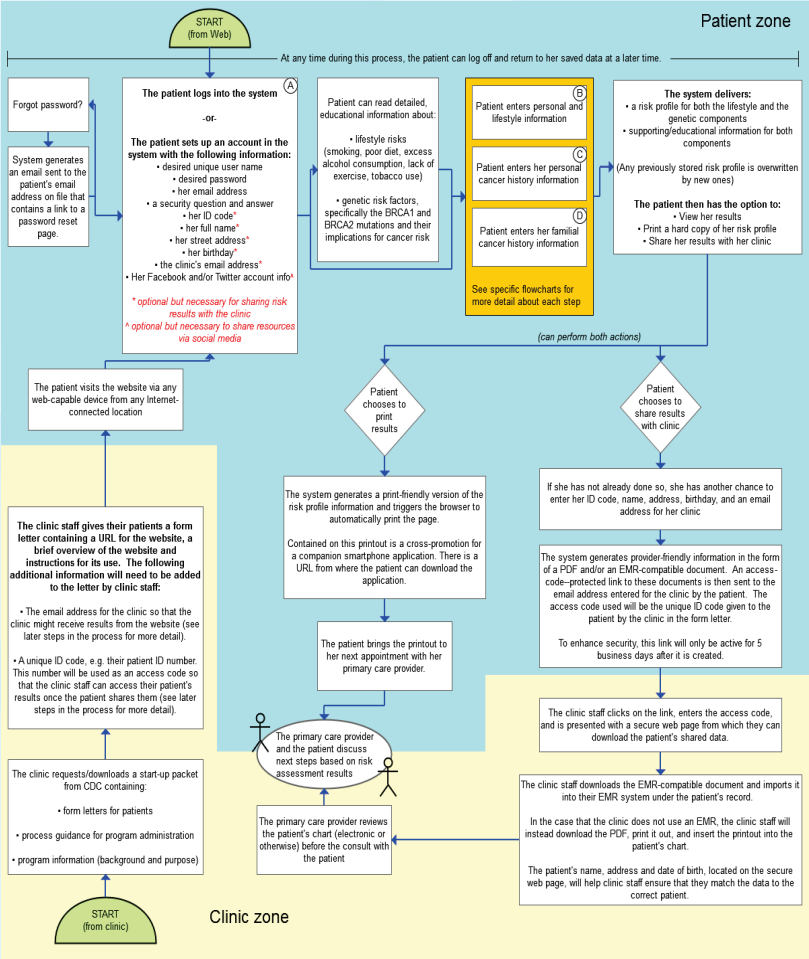
Two zones of responsibility:

Patient Zone:

- Responsible for learning about breast and ovarian cancer risk factors
- Responsible for taking the risk assessment

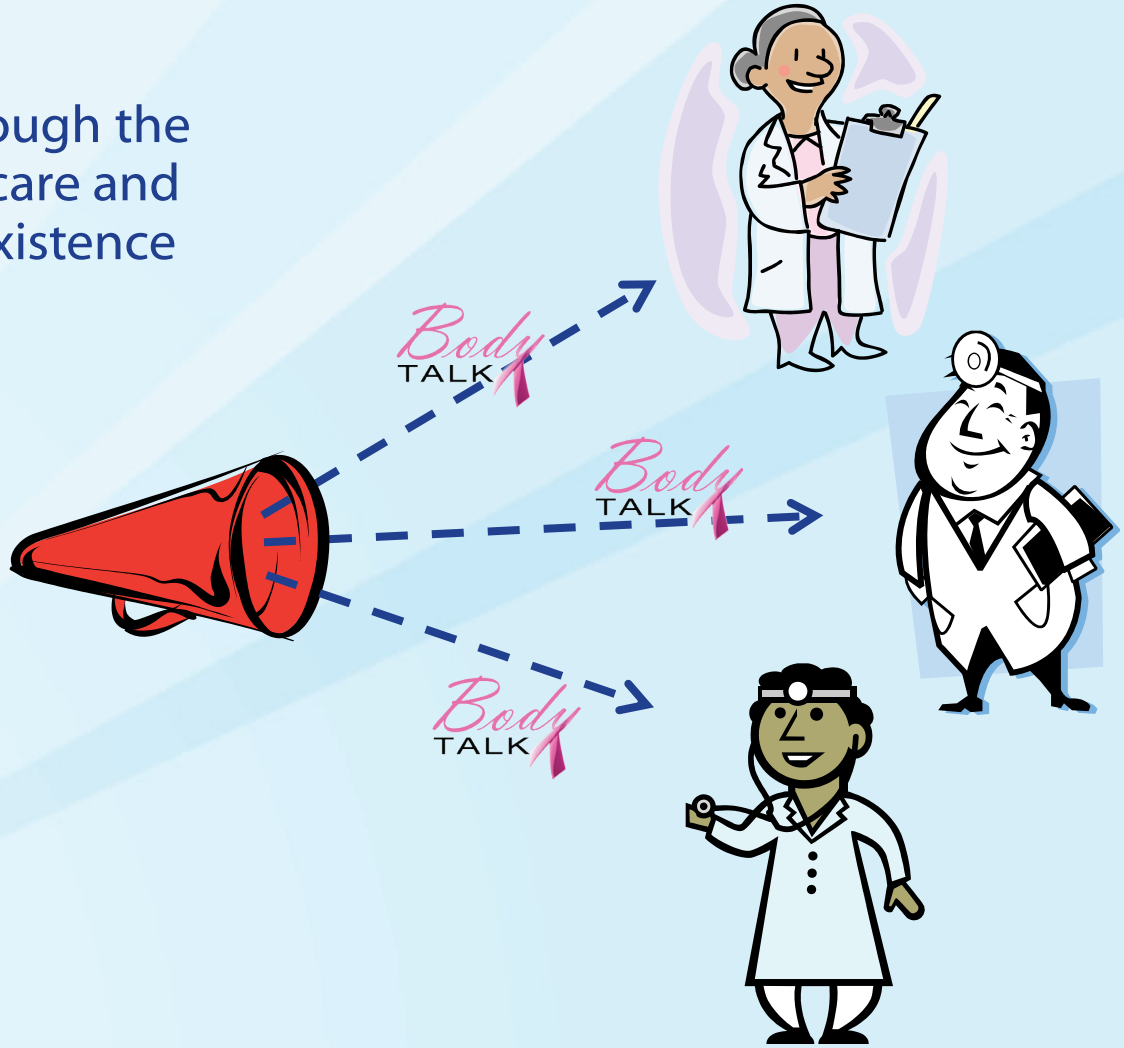
Clinic Zone:

- Responsible for sending the patient to the site and processing that patient's risk profile data.



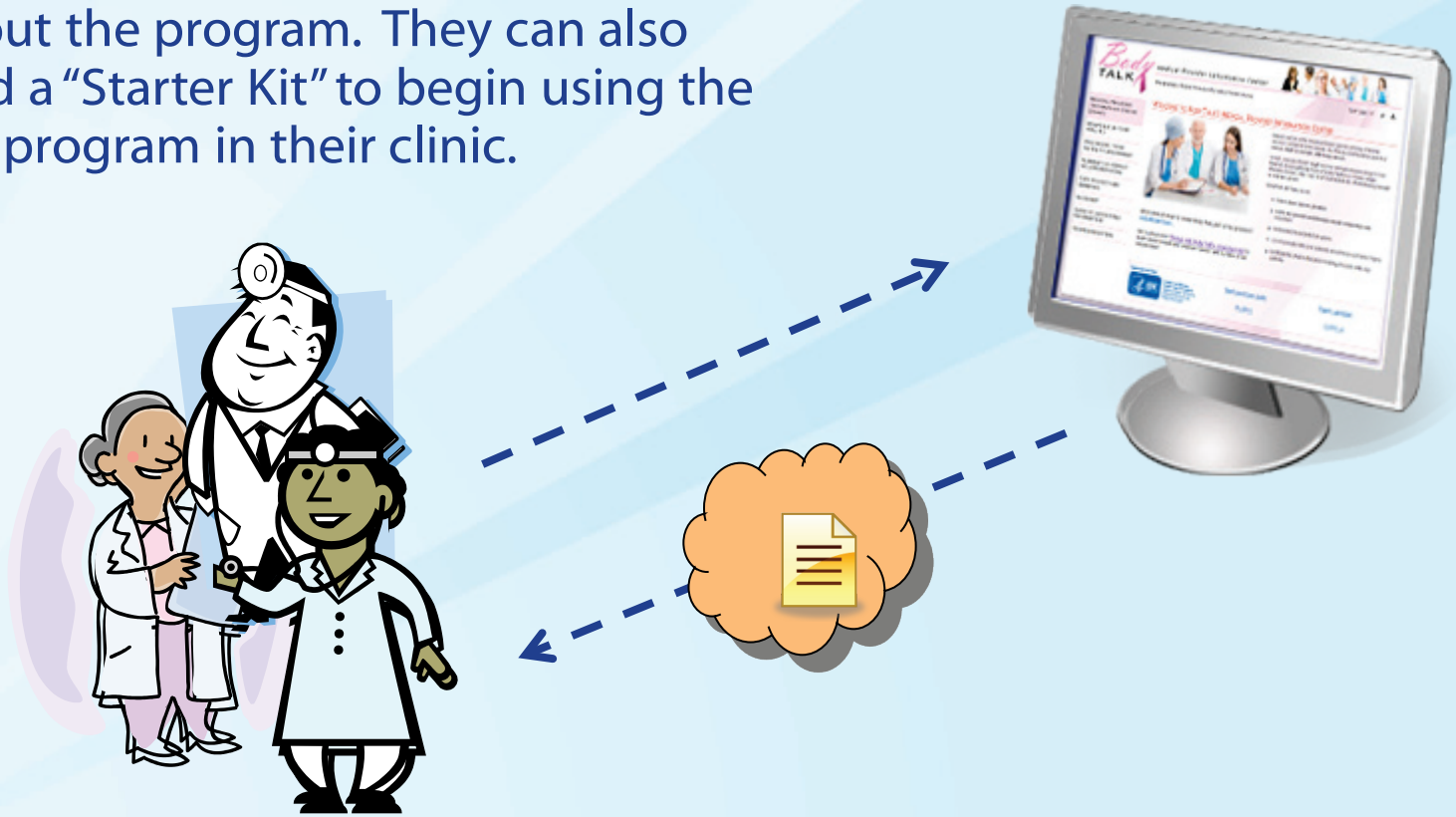
How BodyTalk Works

CDC will communicate through the usual channels to primary care and OB/Gyn clinics about the existence of the BodyTalk program.



How BodyTalk Works

This communication will direct clinical staff to the BodyTalk website where they can learn more about the program. They can also download a "Starter Kit" to begin using the BodyTalk program in their clinic.



How BodyTalk Works

The "Starter Kit" contains:

- A "Welcome letter" used to educate clinical staff about the mission and purpose of the BodyTalk program. This includes a link to the section of the BodyTalk site that contains educational materials for physicians.
- A detailed set of instructions about how to use BodyTalk in the clinic's practice.
- A customizable form letter that clinics can give out to their patients whom they feel should participate in the BodyTalk program

How BodyTalk Works

In addition to instructions, the patient's form letter contains the following elements that the patient will need to set up an account and to be able to share data with the clinic:

- The URL for the BodyTalk website
- A unique reference number for the patient within that clinic.
- An email address for the clinic

How BodyTalk Works

The patient visits the website and educates herself about breast and ovarian cancer risk. She does not need to create an account to see educational content.

Topics include:

- What is cancer and who is at risk?
- How can cancer run in families?
- How can BRCA1 and BRCA2 gene mutations influence cancer risk?
- How can lifestyle habits influence cancer risk?
- How BodyTalk can help you know your risk

How BodyTalk Works

The patient can also access a library of reference/resource links to other educational materials hosted by organizations across the cancer community.

Partner sites could include:

- Other CDC centers
- The American Cancer Society
- The National Cancer Institute
- GeneTests

This link library will be searchable and can be automatically tailored to the particular patient if she has completed her risk assessment.

How BodyTalk Works

The patient then signs up for an account in order to take the risk assessment. Assessment elements include:

- Basic demographic information (age, gender, ethnicity, etc.)
- Questions about the patient's lifestyle choices, e.g. tobacco use, alcohol consumption, exercise habits, and dietary tendencies.
- The patient's personal cancer history.
- The patient's family cancer history.

How BodyTalk Works

The patient calculates her risk profile. Risk profile results are grouped into five categories:

- BRCA1/2 mutation risk
- Tobacco use
- Alcohol consumption
- Body Mass Index ("Healthy Weight")
- Diet
- Exercise

How BodyTalk Works

In case of a "risky" status for any lifestyle-based results, the patient is asked to rate how willing she is to change this behavior. Tailored content is presented to the patient based on her willingness to change.

Options include:

- I'm not ready to change
- I'm thinking about changing
- I'm planning to change
- I'm taking action to change

How BodyTalk Works

Once the patient is finished reviewing and rating her risk profile, she can print her results.

- The system bundles up all risk result sections and appends consumer-friendly discussion guide to help the patient talk to her physician.
- The system then generates a single document, suitable for printing from the browser.
- The patient brings this printout with her to her next consult with her physician.

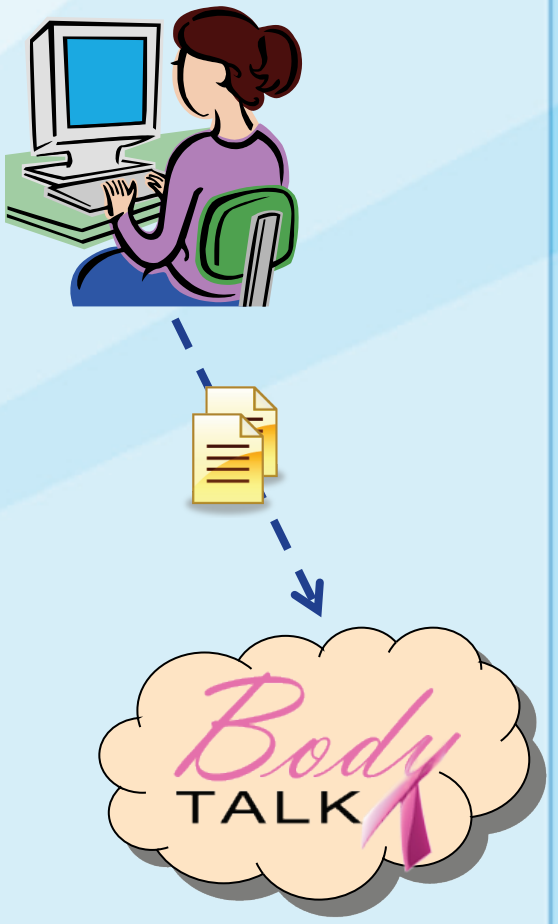
How BodyTalk Works

In addition to printing, the patient can also click a link to securely share her results electronically with her clinic.

The system bundles up all risk result sections and appends physician-friendly discussion guides that help the physician talk to their patient.

The system creates two output files that are identical to each other in content:

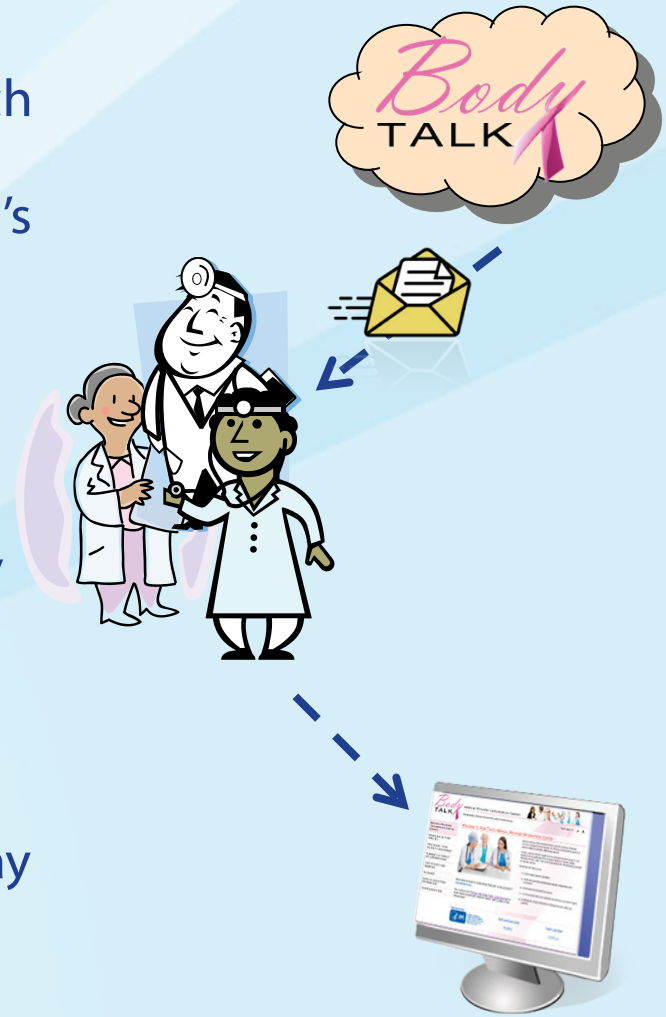
- A PDF file for printing.
- A Clinical Document Architecture (CDA) file for direct importation into an electronic medical record system (EMR).



How BodyTalk Works

BodyTalk then sends an email to the clinic which contains a link back to the BodyTalk website where the clinic staff can download the patient's shared results.

- The link is good only for 14 days after it is created.
- The clinic is asked for a password before they can access the download site. The reference number given to the patient acts as this password.
- Upon successful authentication, the clinic may download both the PDF and the CDA files.

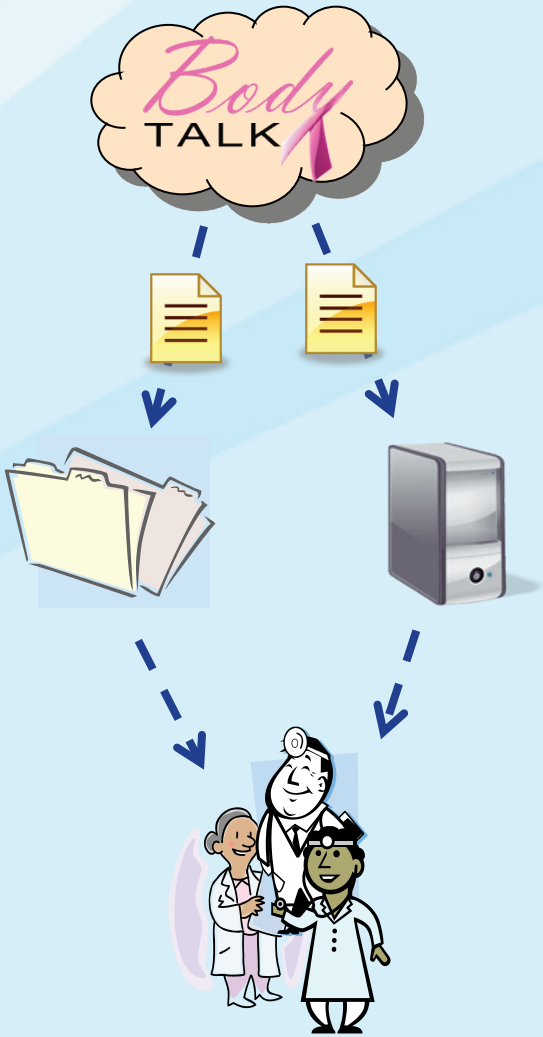


How BodyTalk Works

Clinic staff insert the shared results into the correct patient's chart and therefore into the physician's regular clinical workflow.

- The PDF is printed and manually inserted into patient's chart
- The CDA is imported into the patient's electronic medical record.

The physician then prepares for the consult with the patient as he/she normally would except now there is a new piece of information to discuss.



How BodyTalk Works

Both patient and physician come to their next consultation prepared:

- The two parties can engage in shared decision making instead of just data gathering.
- The discussion guides help make the 15 minutes (on average) physicians spend with their patients more efficient.
- The physician has an improved understanding, and documentation, of the patient's family cancer history.

Website Walkthrough

Learn. Know. Act.

Enter username | Enter password | Log in

Forgot password | Register for an account

You are here: Medical Provider Information Center (Home)

TEXT SIZE: a A A

- HOME
- LEARN THE FACTS
- ASSESS YOUR RISK
- RESOURCE LINK LIBRARY
- LOCATE SCREENING FACILITIES

MEDICAL PROVIDERS

Visit the Medical Provider Information Center for information about:

- breast and ovarian cancer
- the BRCA1&2 gene mutations
- talking to patients about breast and ovarian cancer risk factors

Take me there >>

WELCOME TO BODYTALK

Breast cancer is the most common cancer among American women, except for skin cancer. It is the second leading cause of cancer death in women, after lung cancer.

In fact, one out of every eight women will get breast cancer in her lifetime. If you have a family history or make certain lifestyle choices, you may be at increased risk of developing breast or ovarian cancer. Knowing your risk factors is so important. It could save your life.

BodyTalk will help you to:

1. Learn

In the *Learn The Facts* section, you will learn about breast cancer and ovarian cancer and how both genetics and lifetyle choices can influence cancer risk.

2. Know

Answer a few questions about your, and your family's, cancer history and our risk

3.

Sponsored by: Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion

Learn. Know. Act.

Logged in as: Someone001

Account settings | Log out

You are here: BodyTalk Home > Assess Your Risk > Personal Cancer History

TEXT SIZE: a A A

- HOME
- LEARN THE FACTS
- ASSESS YOUR RISK
  - Personal Profile
  - Personal Cancer History
  - Family Cancer History
  - Results
- RESOURCE LINK LIBRARY
- LOCATE SCREENING FACILITIES

PERSONAL CANCER HISTORY

It is important for an accurate risk assessment that you enter your own, personal cancer history.

NOTE: There is a difference between breast cancer and other cancers that start in a different part of the body and move to the breast. Please, make sure that you record a diagnosis only if you have been specifically diagnosed with breast cancer.

Calculate your results

BREAST CANCER HISTORY

Have you been diagnosed with breast cancer? No

If so, at what age?

Have you been diagnosed with breast cancer in both breasts? No

If so, at what age were you diagnosed in

OVARIAN CANCER HISTORY

Have you been diagnosed with ovarian cancer? No

If so, at what age?

Have you had your ovaries removed? No

If so, at what age?

rsonal profile

Next: Family cancer history >>

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Learn. Know. Act.

Logged in as: Someone001

Account settings | Log out

You are here: BodyTalk Home > Assess Your Risk > Results - BRCA

TEXT SIZE: a A A

- HOME
- LEARN THE FACTS
- ASSESS YOUR RISK
  - Personal Profile
  - Personal Cancer History
  - Family Cancer History
  - Results
- RESOURCE LINK LIBRARY
- LOCATE SCREENING FACILITIES

RESULTS

This "Results" section is your action plan. It provides tips on talking to your doctor, lists the questions you want to ask your doctor, and depicts your family tree and family cancer history. Bring a print out of this section to your next appointment and share it with your doctor.

We also recommend that you share your results with your doctor (see "Actions" links above). By sharing, you'll allow your doctor's office, and only your doctor's office, to download your risk results for their own records. This will help both you and your doctor to have a more effective conversation.

BRCA1/BRCA2 | Tobacco | Alcohol | Healthy Weight | Diet | Exercise

BRCA1/BRCA2 MUTATION RISK

You are *[not] at increased risk* for having a BRCA1 or BRCA2 gene mutation.

Now that you know your chances of having a BRCA1 or BRCA2 gene mutation, you and your doctor should discuss these results and your family history and decide together if genetic testing makes sense.

Remember, this assessment simply tells you your chances of having a BRCA1 or BRCA2 mutation. It cannot tell if you actually have a mutation, and it cannot tell if you have cancer.

ACTIONS:

- Print all results
- Share all results with your doctor

TIPS FOR TALKING WITH YOUR DOCTOR

Give information.
Tell your health care provider what you know about your family's history of cancer and your lifestyle risk factors. Do not wait to be asked.

Ask questions.
Ask your health care provider any questions you have, especially if you don't understand something. Start at the beginning of the visit - don't wait until the end of the visit when time is short.

Write down questions before your visit.
This activity will help you remember what to ask and help clarify your concerns.

Take notes.
It can be hard to remember everything your health care provider tells you. Bring a notebook or a piece of paper to take notes during your visit. You can also bring a family member or friend with you

GENE MUTATION RISK VS. CANCER RISK

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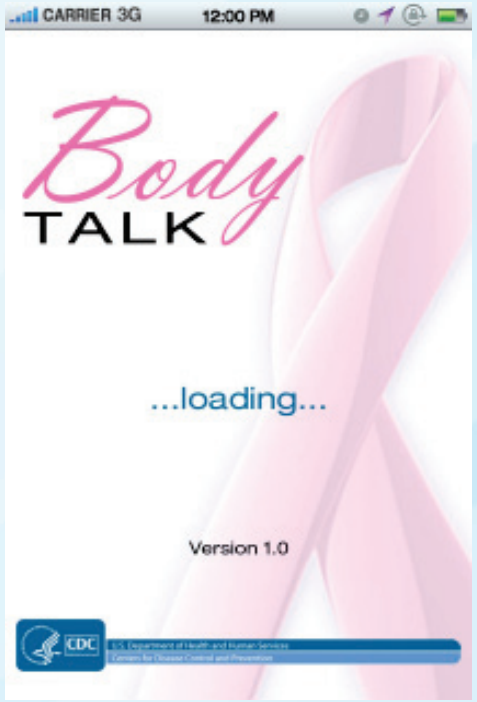
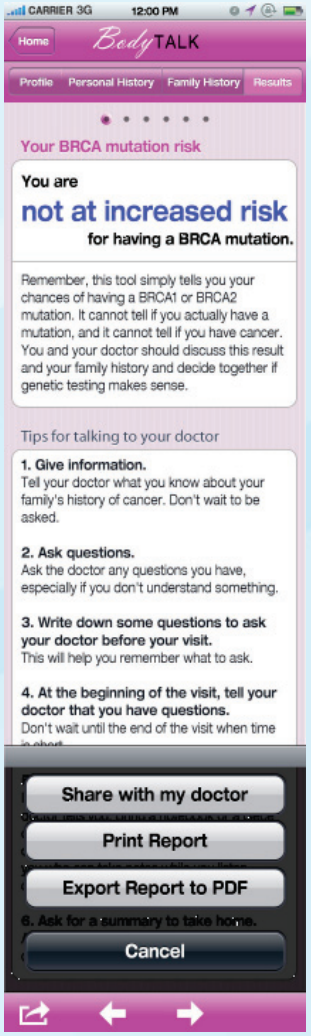
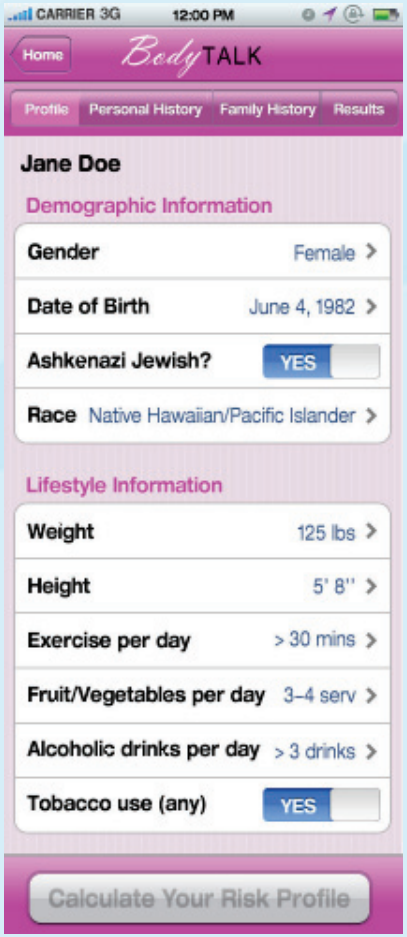
Smartphone Screenshots







Concept Testing - Goals

Our goals for this round of testing were:

- To assess feasibility of implementing BodyTalk in a primary care or OB/Gyn practice
- To assess readability and comprehension of the marketing and "Starter Kit" materials
- To assess the user experience of the website, most notably the risk assessment steps
- To assess the informational needs and desires that young women would have from this site.

Concept Testing - Background

Conceptual testing took place between July and August 2011. We contracted with a company called User Insight to conduct the actual interview sessions.

We conducted:

- Remote sessions - conducted via web conference and telephone
- On site sessions – conducted at a respondent's place of business
- In-lab sessions – conducted at User Insight's offices in Atlanta

On average, each session lasted for one hour.

Concept Testing - Background

Market segmentation:

Nine (9) clinic administrators

- Large practice
- Small practice

Nine (9) physicians

- Primary care
- OB/Gyn

Nine (9) young women,

- Previously diagnosed
- Not previously diagnosed

Concept Testing - Background

Testing artifacts:

Clinic administrators and Physicians

- Marketing letter
- Welcome letter
- BodyTalk instructions
- Patient form letter
- Website prototype
- Discussion guides

Young women

- Patient form letter
- Website prototype
- Discussion guides

Concept Testing – Top-level Findings

Challenges:

- Physicians not confident that patients will be able to complete the assessment unaided, thereby skewing results
- Concerned about being reimbursed for time spent with the program

Positives:

- Confident clinic could support the Body Talk process
- Appreciates the inclusion of discussion guides as it helps frame the discussion of the assessment with the patient

Next Steps

Internal CDC release (October 2011)

- Content review and clearance.
- Acceptance testing.
- Make any necessary refinements.

Pilot release (TBD)

- Release BodyTalk to a small but diverse set of primary care and OB/Gyn clinics across the country.
- Evaluate the program in terms of real-life usage.
- Make any necessary refinements.

"Go live" release (TBD)

- Release the website under a custom URL.
- Submit smartphone apps to iTunes app store and Android Marketplace for approval and dissemination.
- Implement communication plan.

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For more information please contact Centers for Disease Control and Prevention

1600 Clifton Road NE, Atlanta, GA 30333
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E-mail: cdcinfo@cdc.gov Web: www.cdc.gov

National Center for Chronic Disease Prevention and Health Promotion
Division of Cancer Prevention and Control