Web-based family history collection and assessment

Louise Acheson, MD, MS
Dept. of Family Medicine
Case Western Reserve University

Outline

- Why?
- The tools
- Going on-line
- Methods of inviting participants
- Uptake
- Patients' responses
- Clinicians' responses
- Pitfalls

Web-based family history collection and assessment:

Why ?

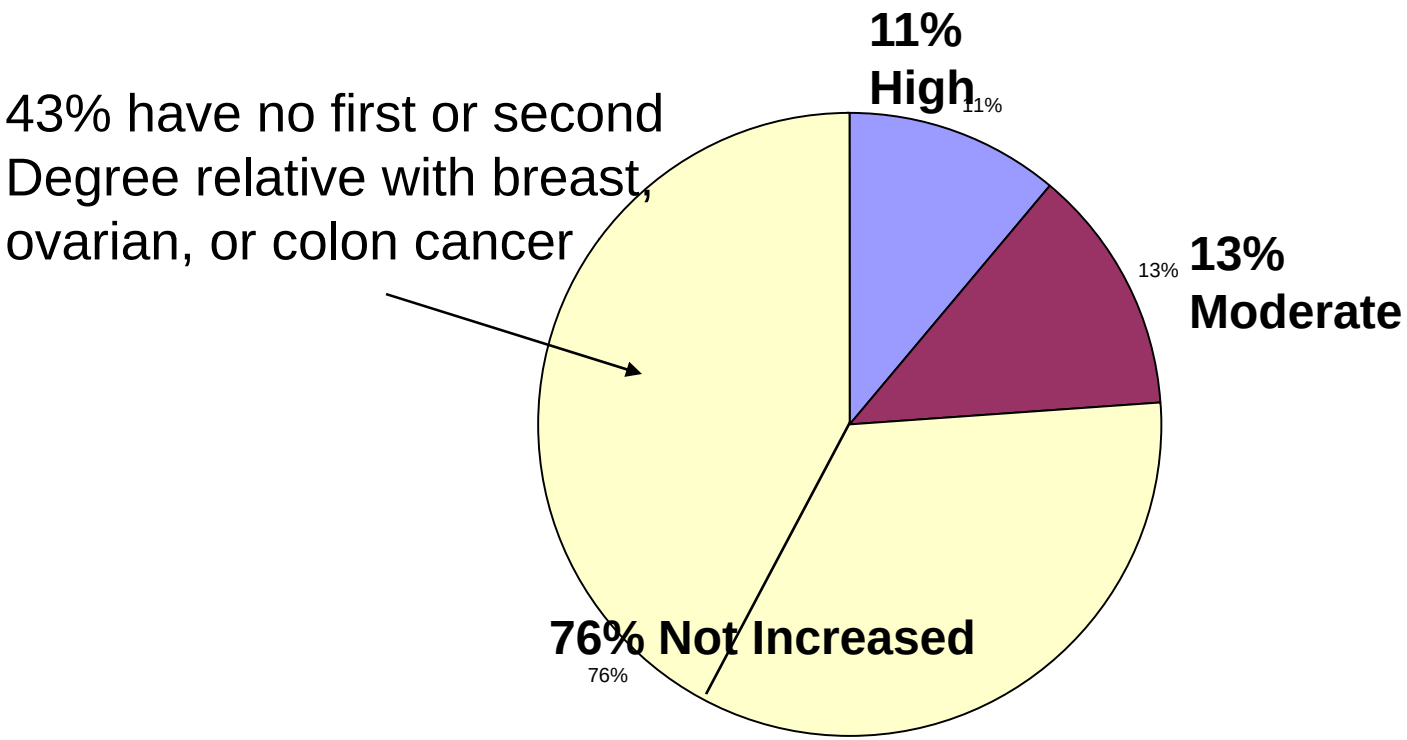
- Feasibility:
  - During a visit, there's not enough time for very detailed family history.

Family History-taking in Direct Observation of Primary Care

- FH discussed in 0 to 81% of family practice visits. 51% of new patients
- Average discussion lasted 2 minutes.
- 11% of practicing FPs' patient charts had a family tree diagram.
- 37% of patients' charts had a notation about a family history of breast cancer. 37% for colon cancer.

  - Medalie et al. J Family Practice 1998;46:390-96
  - Acheson et al. Genetics in Medicine 2000;2:180-85

Family History-based risk for Breast Cancer



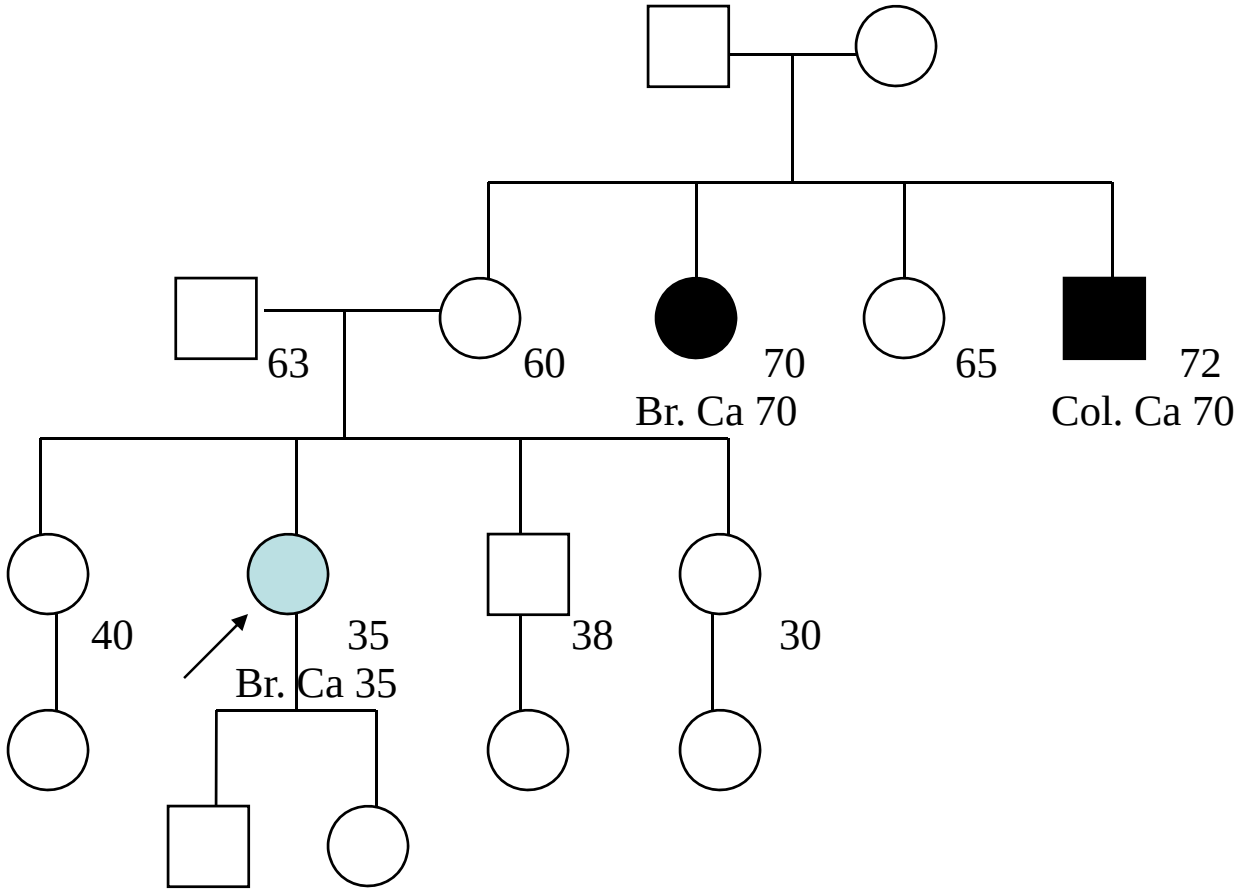
Family Healthware
(women, mean age 51)

September, 2005:
US Preventive Services Task Force

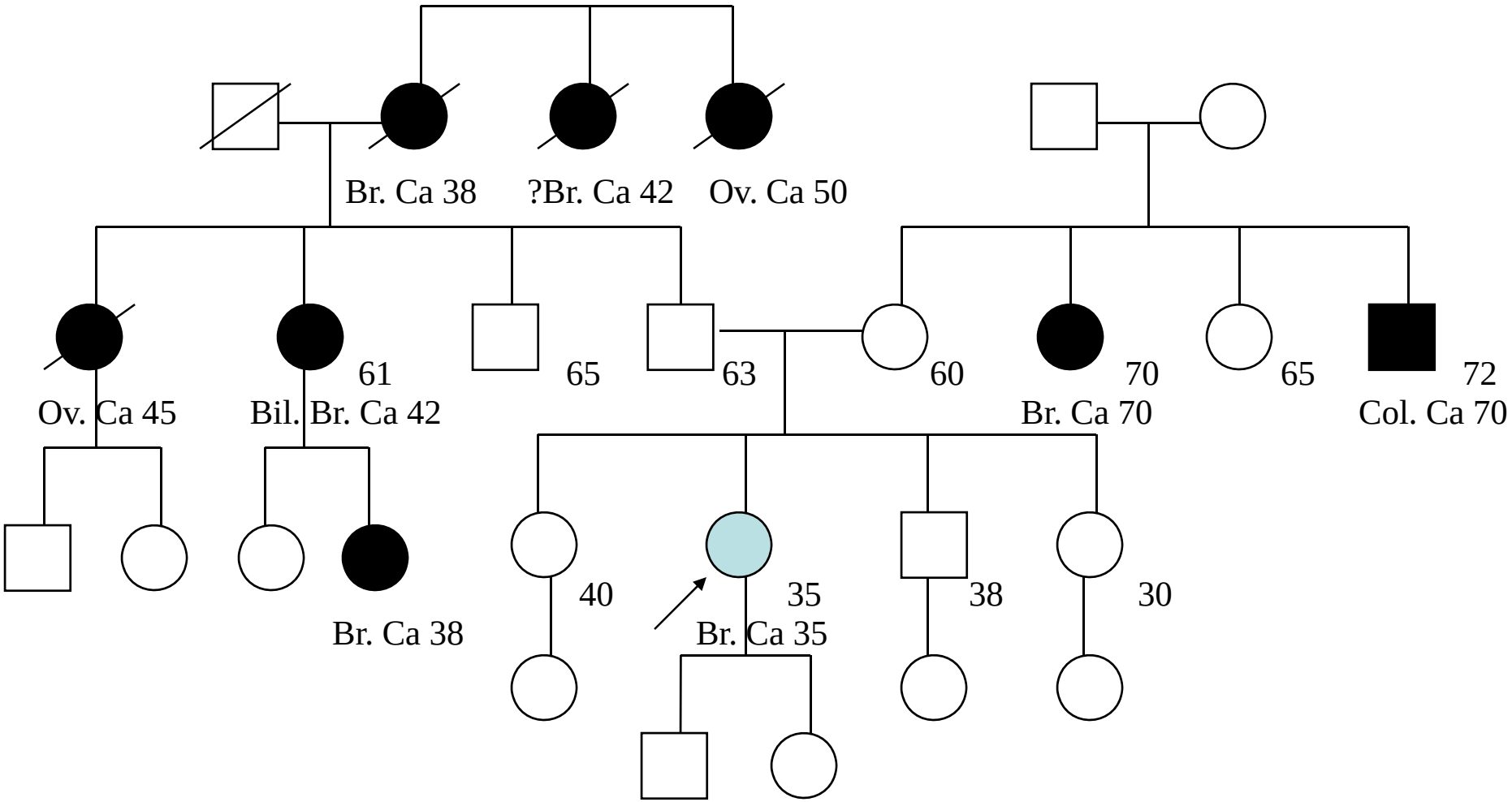
- Recommends that women whose family history meets criteria for increased risk of a deleterious mutation in BRCA1 or BRCA2 genes be referred for genetic counseling and possible testing.

- *Annals Intern Med* Sept. 6, 2005; 43:355-61

Recognizing a High Risk Family May Require Detailed Family History



Including both sides of family and more than first degree relatives.



Clinicians don't know detailed family history

- Data from primary care and oncology practice show that recorded family medical history has been insufficient for cancer risk assessment.
  - Age at diagnosis missing
  - Ovarian cancer missing
  - FH not updated
  - Graphical FH's (pedigrees) are not available

[Sifri, Sweet, Frezzo, Medalie]

Why ?

- Feasibility:

  .

- Decision support:
  - Complex and changing risk assessment and risk-based recommendations.

Tool could prompt actions based on family history

- To take a history
- To clarify information
- To communicate with someone
- Preventive care and screening appropriate for level of risk

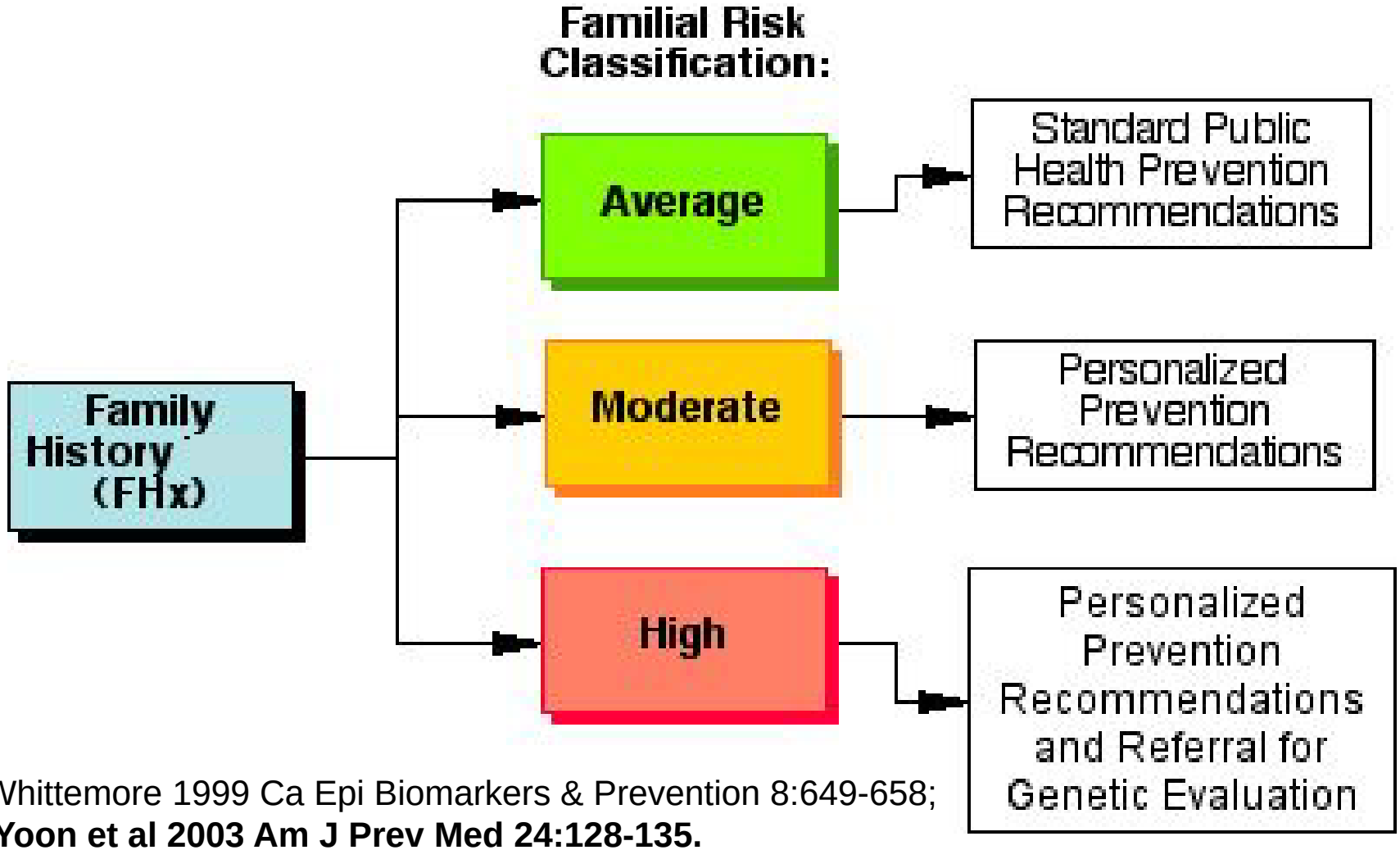
Risk assessment can be built in

- Familial risk
- Epidemiologic risk

Why ?

- Feasibility:
- Decision support:
- Research:
  - Evidence is lacking about the usefulness of family history-based care.
  - How does FH fit into “personalized medicine”?

Model for Risk-Appropriate Preventive Care



Whittemore 1999 Ca Epi Biomarkers & Prevention 8:649-658;
Yoon et al 2003 Am J Prev Med 24:128-135.

Collection and Use of Family History for Cancer Prevention in Primary Care

#159 October, 2007 Qureshi N et al.

Systematic review **AHRQ Evidence Report**

- Accuracy of reporting family history of cancer
- Family History Tools to capture family history
- Risk assessment tools to promote recognition and appropriate management of familial cancer risk in primary care

AHRQ Evidence Review of Tools to Capture Family History in Primary Care

- 18 different tools evaluated and published
  - & others without published evaluations
  - Paper and Computer; Clinician vs. Patient

- Self-administered tools perform well compared to an interview by a geneticist
- and improve upon current practice,
- capture family history suitable for use in cancer risk assessment.

Evidence for effectiveness of Risk Assessment Tools (RATs)

to interpret family history, with purpose of promoting recommended clinical actions?

- Only 3 tools evaluated in controlled trials. (and now CDC Family Healthware Trial is pending).

- RATs designed for clinicians to use:
  - Clinicians didn't use the risk assessment tool.
    - [Schroy (PDA), Wilson (multicomponent), others]
  - When used [Emery] it did increase appropriateness and number of referrals to genetics consultation.

Evidence of RATs' Effectiveness is not in yet.

- RATs designed for laypeople to use:
  - CRIS [Skinner] increased discussions of colonoscopy, genetics referral, and use of tamoxifen.
  - JamesLink did not result in more genetics consults.
  - We found that only 16% of healthy people invited in Family Healthware study used tool. Effects on preventive care pending.
  - Hughes and colleagues made it routine part of mammography and have had thousands use computer intake form [Jones]

- Insufficient evidence, so far, as to whether RATs do promote risk-appropriate preventive behaviors, or do indeed result in early detection or prevention of cancer, save lives.

Web-based Family History Tools

Address http://myfamily.case.edu/Login.aspx

Google Go Bookmarks 151 blocked Check AutoLink

Family Healthware
Using Family History to Promote Health

CDC

Welcome to Family Healthware

Family Healthware is a free tool that collects information on your:

- lifestyle behaviors
- use of screening tests
- family history of six major diseases

and produces a personalized report that:

- analyzes your family history as a risk factor for disease
- recommends screening, lifestyle and other changes to improve your health.

Username:

Password:

Go

Forgot your username or password?

Click to learn about:

Family Healthware

Family History & Health

Family Healthware is not designed to replace medical advice and discussions with a health professional. You should talk to your health professional before making a decision about your medical care.

What's innovative about the CDC Tool?

- Prioritizes prevention for multiple diseases, not just one at a time.
- Includes lifestyle, BMI, and **family history** risk in prevention recommendations.
- Web-based tool, self-administered. Provides immediate report with **family tree**.

Family Healthware
Using Family History to Promote Health

Surgeon General's Family History Tool

http://www.hhs.gov/familyhistory

G. R. E. A. T.

GENETIC RISK EASY ASSESSMENT TOOL

Welcome

Welcome to the Genetic Risk Easy Assessment Tool. (GREAT) at Case Western Reserve University.

Your family health history is valuable. It may show patterns that suggest what you and your relatives could do to stay healthy. It may show patterns that could reveal a genetic basis for diseases in the family.

Our goal is to make it easy to record and use your family medical information---for yourself, for your health care, for your family, or to contribute to medical research.

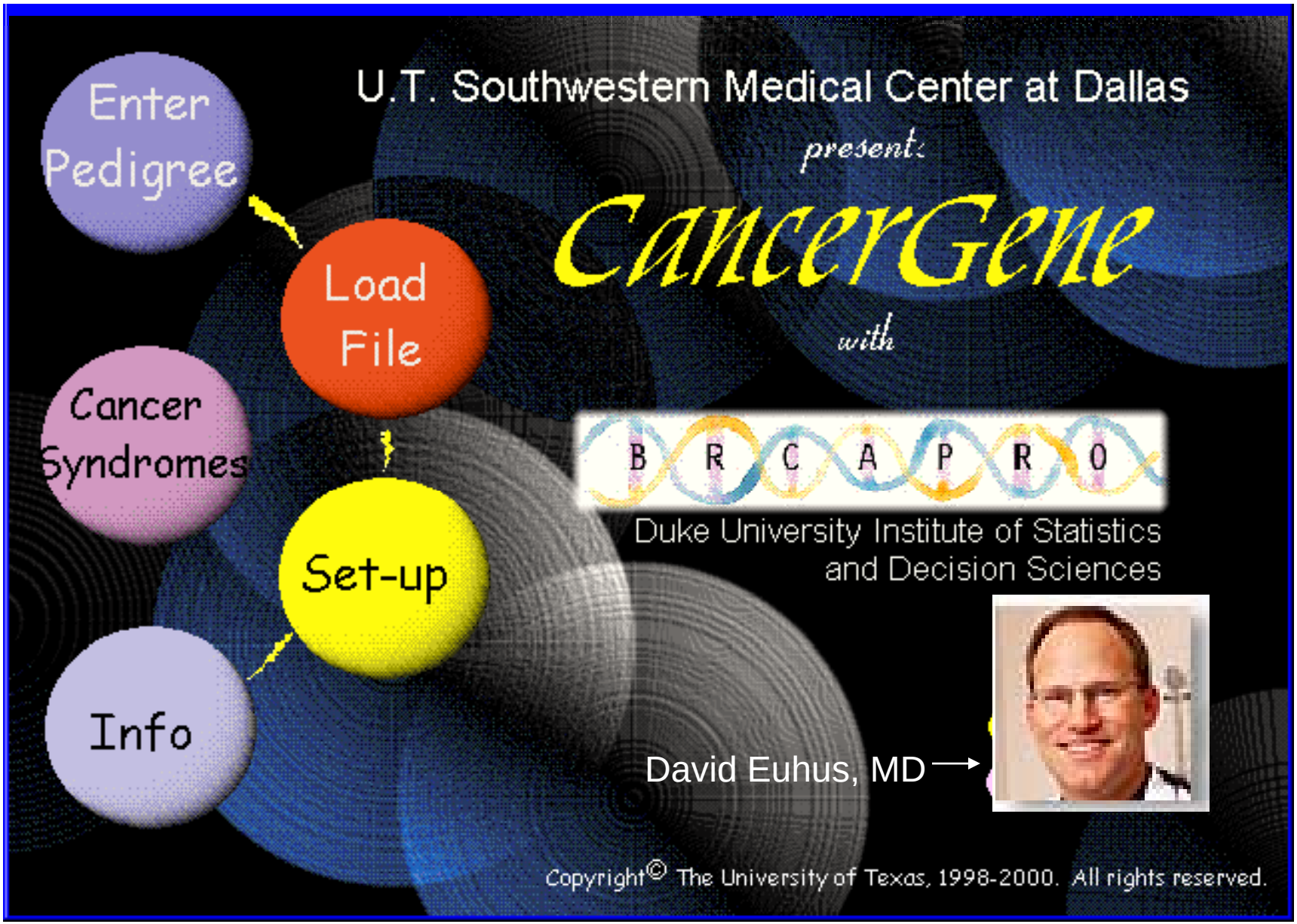
Record your family medical history and receive your family tree and family risk prevention report

Web-based GREAT

https://family.case.edu

- https://family.case.edu
- Self-administered, web-based family history questionnaire and database
- Focuses on family history of cancer
- Generates and displays family tree
- Interprets family history of cancer
- Connects with Cancergene for empirical risk and mutation probability models

http://www8.utsouthwestern.edu/utsw/cda/dept47829/files/65844.html

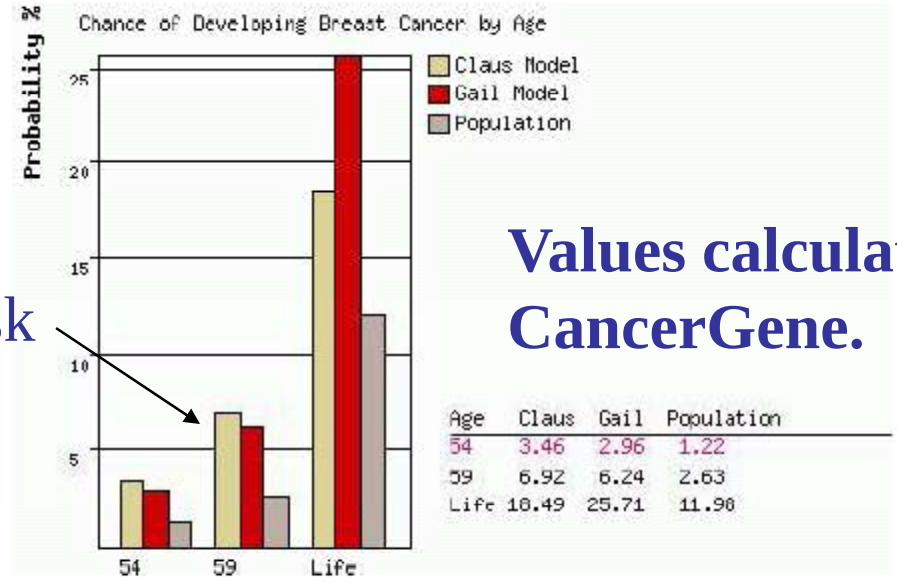


Example report for Clinician, showing 5-year, 10-year, Lifetime Breast Ca Risks: Gail model, Claus model.

UserID: 1010–1018–1060 November 2nd 2005
Version 1 Page 6 of 8

Breast Cancer Risk and Prevention

This graph shows the chance of developing breast cancer based on the information you provided during the survey, please talk to your doctor about the results.



Age	Claus	Gail	Population
54	3.46	2.96	1.22
59	6.92	6.24	2.63
Life	18.49	25.71	11.98

More than double the General population risk

Values calculated by CancerGene.

Know Your Risk:

BRCA Mutation probability can be calculated in CancerGene, based on family history recorded by a layperson via an Internet tool such as G. R. E. A. T. Genetic Risk Easy Assessment Tool

	Proband Probability
BRCA1	
Couch (U. Penn)	0.032
Shattuck-Eidens (Myriad I)	0.077
BRCAPRO	0.021
BRCA2	
BRCAPRO	0.004
BRCA1 or 2	
NCI CART	none
Myriad.com (MyriadII)	0.105
BRCAPRO	0.026

Pedigree Information
Ashkenazi family: **no**
Number of family members: **11**
Number with breast cancer only: **2**
Number with ovarian cancer only: **0**
Number both breast and ovarian cancer: **0**
Number with bilateral breast cancer: **0**

Ontario FHAT: 9

Values expressed as probabilities, not percents

"none" means no calculation possible

***CancerGene*Version 3.3**
Myriad.com table 08/23/2000

G. R. E. A. T.
GENETIC RISK EASY ASSESSMENT TOOL

Personal Report

Save or print the report. Whether or not there is any family history of cancer, your family health history is important for your medical care. You can save this report in your computer and print it for your records. You can update it by returning to https://family.case.edu at any time. You will need your password. Your PIN is at the top of this page.

Use Family History for Prevention

Talk with your doctor or a health care professional about what your family medical history means for your health, what next steps to take and what you might want to say to your relatives.

Many cancers are preventable, and the earlier they are detected, the more easily they're cured. If you know that your family medical history increases your risk for cancer, you can take steps to prevent it or detect it in its earliest stages.

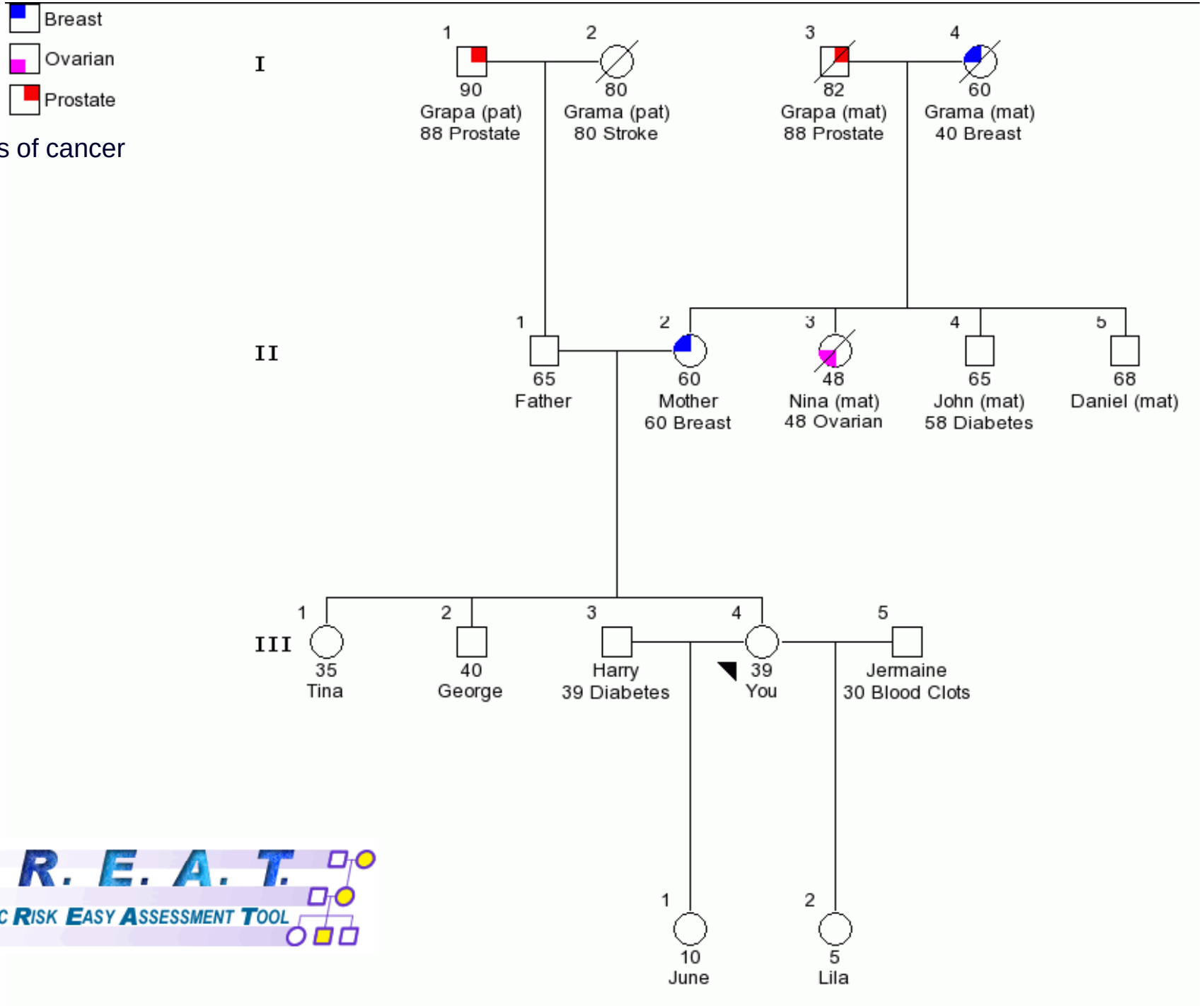
Cautions: *[Disclaimer]*

The information about disease risk and prevention in this report is general and may not apply in your situation. It is not to be taken as medical advice.

This information must be interpreted by a health professional in the context of a person's entire medical history.

Family health information is personal and private.

Your family medical history contains private health information, not only about you, but about others in your family. It is up to you to take steps to keep it safe, such as keeping copies or printouts in a safe place and not sharing your password.



Types of cancer

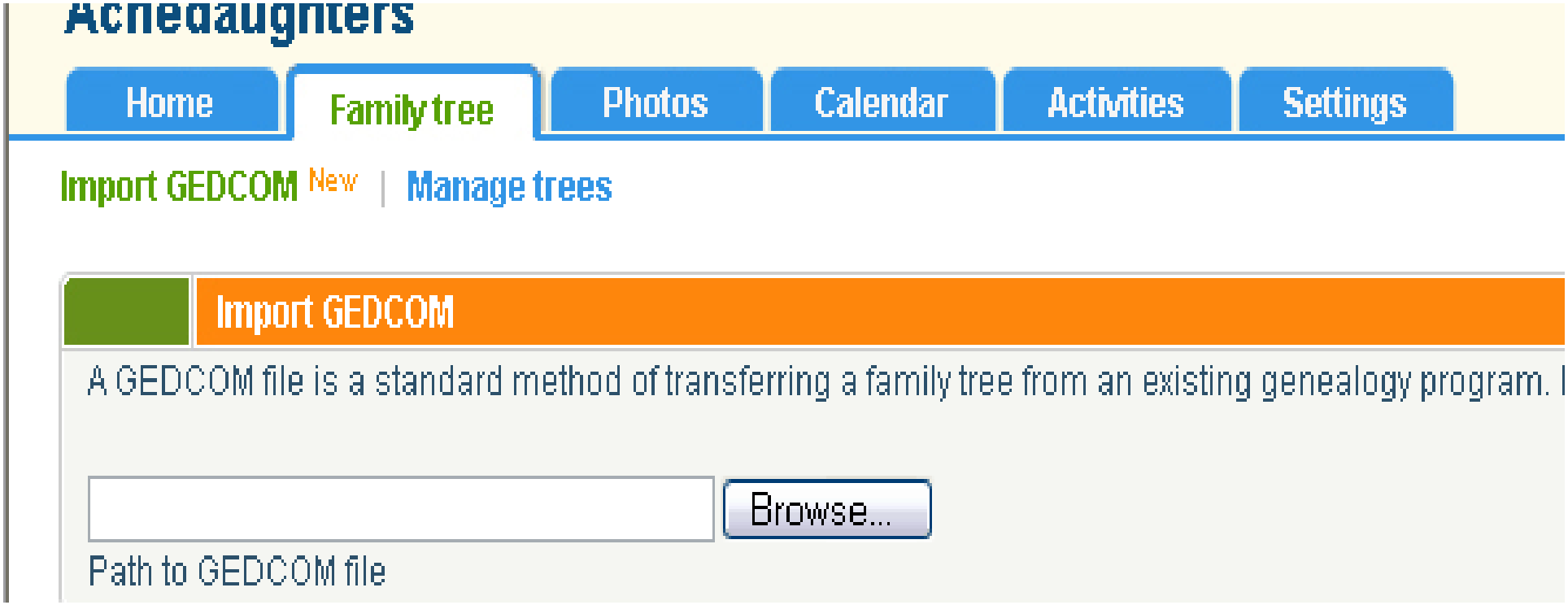
G. R. E. A. T.
GENETIC RISK EASY ASSESSMENT TOOL

Community-Centered Family Health History---Genetic Alliance

Social Networking Approach

Narrative-based; Structured Questionnaires

Geneology: Social Networking *and* GEDCOM



Going on-line

Selects for those with internet use, comfortable on-line

Older folks using the internet

- It never ceases to amaze me when my 90-year-olds come in and tell me about the e-mails they are exchanging with their grandchildren.

- A sizeable minority are computer savvy. There's a large Medicare retired population and some of those people, wealthier Medicare pts, were more interested and more computer savvy. We have a fairly large Medicaid population. We have an EMR and we are trying to initiate communication with patients by email. I will guess that maybe 10-20% are using the system.

Internet access

- RURAL: You know, it's surprising. We are beyond rural-we're considered frontier but it's surprising how many of our patients are hooked up to a computer. Many of them have satellite and some have dial-up out here.

- INNER-CITY: I would definitely use it in my practice with the caveat that I am now in an inner-city clinic and there are people with lower education levels so many of them do not have computers in the home and they're not quite as [internet-]savvy and with less information about the family.

What do women think of using a computer via the internet to record and assess Family History of cancer?

- Christian Simon, PhD, CWRU Dept. of Bioethics, Center for Genetic Research, Ethics, and Law
- Semi-structured interviews with 65 women from the UH Breast Center
- Mean age 57
- 40% African-American
- 48% college graduates

Privacy of Family History of Cancer

- In general, do you feel that information about your family history of cancer is:
  - Absolutely or Very Private 12%
  - Not so private 44%
  - Not private at all 44%
- 97% were comfortable providing FH of cancer to their doctor and thought their family would be too.

Fewer (76%) were comfortable "recording, storing, and sharing your family's history of cancer on a computer and the internet"

	N	%
Very comfortable	16	25%
Mostly comfortable	33	51%
Uncomfortable	12	18%
Very uncomfortable	4	6%

40 (62%) would be interested in using a computer program via the internet to record family's history of cancer

N	Reason:
5	To document and organize information once, save repeated paperwork
8	To document FH for family members, especially future generations
3	To expedite communication of the information
13	To provide information for scientific research
11	Altruism: To help others
	2 specifically mentioned their culture or ethnic group
	4 To support other families in similar situation
6	Nonspecific reason

25 (38%) would NOT be interested in using a computer via the internet to record family's history of cancer

N	Reason
• 10	Privacy and internet security concerns
• 5	Not comfortable using computers
• 5	No need.
– 3	because no family history
• 1	Don't have time
• 4	No reason

GREAT to identify increased risk of HBOC: feasibility study in Breast Center

- Invite women visiting the UHC Breast Center for screening mammograms or breast problems to use the GREAT.
- Offer free genetic counseling to those at high risk.
- Measure uptake, acceptability to users, reasons for declining, prevalence of increased HBOC risk
- Interview women 6 months later to learn what they did in response.

The Family Healthware Impact Trial (FHITr)

- Clinical utility of Family Healthware in primary care practices
- Funded by CDC Cooperative Agreement
- Three Academic Centers
  - Evanston Northwestern Healthcare (suburban Chicago)
  - University of Michigan (Michigan)
  - Case Western Reserve University and AAFP National Research Network (CA, OR, MT, NV, OH, CT, NJ, VA, FL, GA, NC)

Family Healthware
Using Family History to Promote Health

Research questions

- Do participants engage in preventive actions more or less after using Family Healthware, compared to providing baseline data and receiving standard prevention messages?

- Do family doctors think the Family Healthware report is useful?

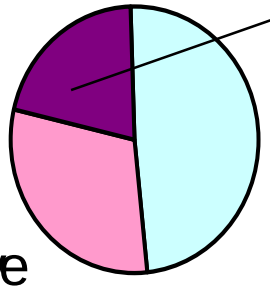
Uptake of invitation to use GREAT after mammogram or breast consultation

prelim. First 5 months 2008

- Invited 2065
  - Mean age 57

~12% high risk?

Have had breast or ovar Ca 22%



No Pers or FH BrOvCa 48%

Have relative with Br or Ov Ca 30%

Declined 194

Consented: 105

- 10% of those with personal or FH or br./ov.ca.

Completed: 67

- 6% of eligible
- Mean age 60
- 16% African-American

Acceptability of GREAT to users

Preliminary N=42

		%
Easy to get around the Web pages		95%
Easy to understand Questions about FMH		97
Time Not too long		100
Personal Report easy to understand		90
Family Tree Interesting		69
Breast and Ovarian Cancer risk easy to understand		85

Concerns of GREAT users

	Incr Risk HBOC (n=11)	Not incr.risk (n=27)
Using GREAT upset me	0	0
I am worried that the personal information might not be kept private	1	6
Concerned about insurance discrimination because of my medical condition	3	11

Methods of inviting participants

- When scheduling appointment
- Letter to patient panel
- At time of appointment
  - Before
  - After
- On the Web

Study participation:

Pts age 35-65, not diagnosed with the 6 diseases

- Michigan:
- 6 practices (7-19 clinicians/ practice; 1 IM, 5 FP)
- invited patient panel screened for eligibility (n=11,956)

  1301 (11%) participated
- Evanston
- 21 practices (1-9 clinicians/ pract; 4 Gyn, 7 FP, 10 IM)
- invited people with upcoming appointments (n=9550)

  2069 (22%) participated
- AAFP-Case
- 14 family practices (1-4 clinicians/ practice)
- invited people with upcoming appointments (n=1614)

  382 (24%) participated

Participant demographics n=3785

2362 intervention, 1423 control: Do not Differ

- White 91%
- Female 70%
- Age 35-65: mean 50.5 yrs
- Educated 71% college grads
- Healthy: 65% excellent or very good
- Overweight Mean BMI 27.3
- Access to medical care:
  - 94% can afford needed care
  - Visits to doctor in past year: mean 4.5

Comments from Family Physicians

Semistructured exit interviews with physicians from 5 of 6 Intervention Group practices

- I think the patients found it really interesting and it definitely made them appreciate more on the effect of their family history on their health.

- The other thing it did was it made them think a little bit more about their bad habits; I think people were little more honest about things like alcohol and smoking because they were doing it on the computer as opposed to being asked by me or another provider.

Made discussing risk-reduction easier

- I thought it generated a lot of conversation around modifiable risk factors

- And to be honest, for me, these are areas where it's really hard to quantify risk factors and family history anyway. So this put it into a nice format which allowed it to be addressed in a fairly rapid fashion but effectively during a visit and that is something that has been sorely lacking in, maybe just in my practice, but maybe in the others too.

- You know lifestyle modification is totally frustrating and very tasking for most people so when you get something that quantifies it for you it's nice. The patients got something to carry home with them

Family history affected treatment

- One of the patients [with diabetes], . . . for example, I found that her mother and father and her aunts had diabetes.. . . My treatment then became more aggressive given this [family history] information.

- For example you ask patients their history like breast cancer: if it's positive you tell your lady don't wait until you turn 50 to have a mammogram, you tell them to go ahead and do it now and you get permission from the insurance company. You become more aggressive. You act upon the information.

Guidance for referral to genetics

- I don't believe in asking questions about stuff we’re not going to do anything about. . . . I just never refer people out to [a geneticist]. This might be an opportunity to change that--since one of the recommendations [is] if there's a high risk for a disease, there's value to send them to a geneticist.

Patient does the work

- Having the patient actually be interactive and taking responsibility-- I think it heightened their interests and also it made them more invested--because they were giving the information and getting it from other family members.

- It would be really nice if I could get a new patient in my practice and say as part of your intake I'd like you to go to this web site and fill this out. The next time I see you in a week we will go over it. I mean we already ask the family history stuff but I'll be honest, I hardly ever use it because it's a lot of work. When it's in a nice easy-to-use format it becomes much easier to access.

Doesn’t fit into acute visit

- Patient comes in for an acute visit and I inquire into the history of their present issue-- I don't think patients felt like the family history tool was for them. . . They didn't see how it was addressing their immediate health need.

Interface with Electronic Medical Record (EMR)

- Being able to hook up with the medical record that's already in place might be a really neat way to disperse the information about health behaviors and family history.

- The way I see it in the future we will have an electronic medical record in each room and in each of them will be a computer. The nurse can come into the room and ask, “While you are waiting for the doctor, could you please complete this questionnaire?”

Conclusions from Preliminary Analyses:

- A minority of primary care and mammography patients are interested in FH assessment at a given time.
- Internet, Computer tools aren't for everyone.
- Multiple modalities will be needed to collect family history
- Many laypeople want to contribute their family history for medical research
- Some think of family history in terms of social networking, mutual support

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