Reaching Underserved Patient Populations: Adaptations for Usability

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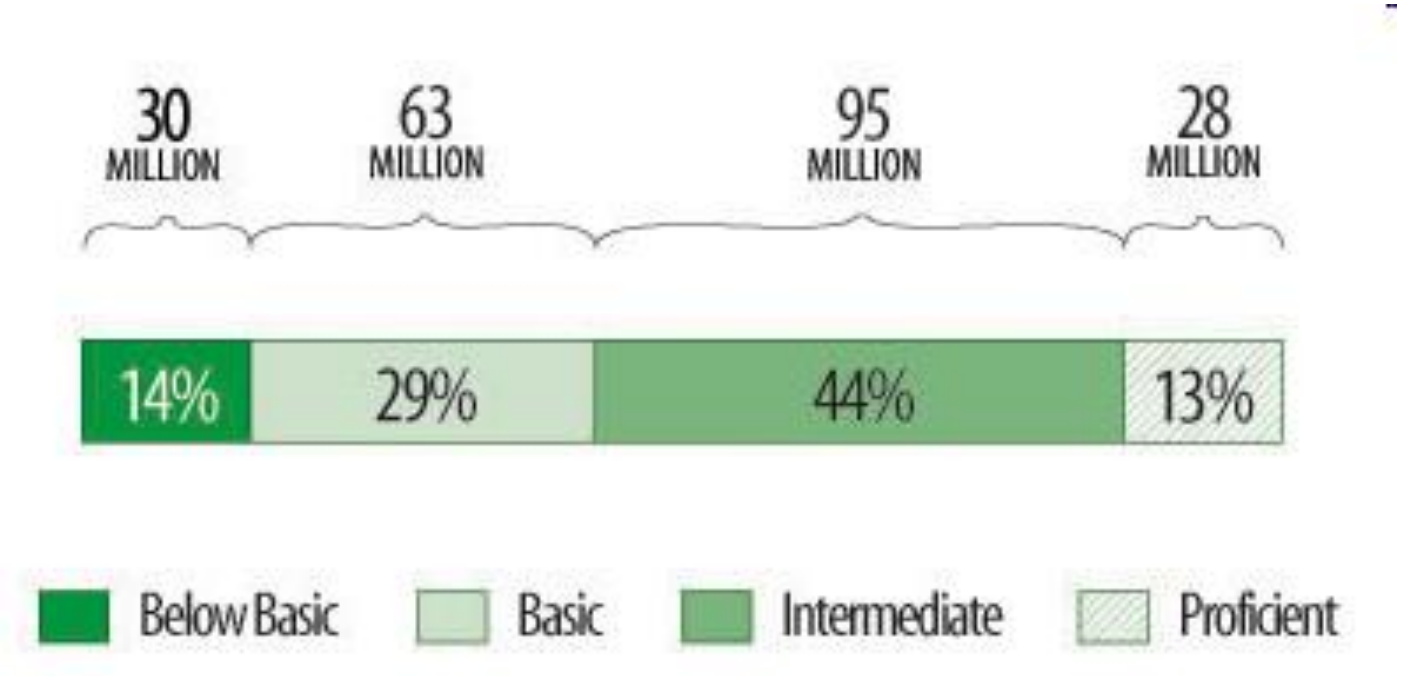
Literacy Skills of U.S. Adults

- average reading level in U.S. is 8th - 9th grade



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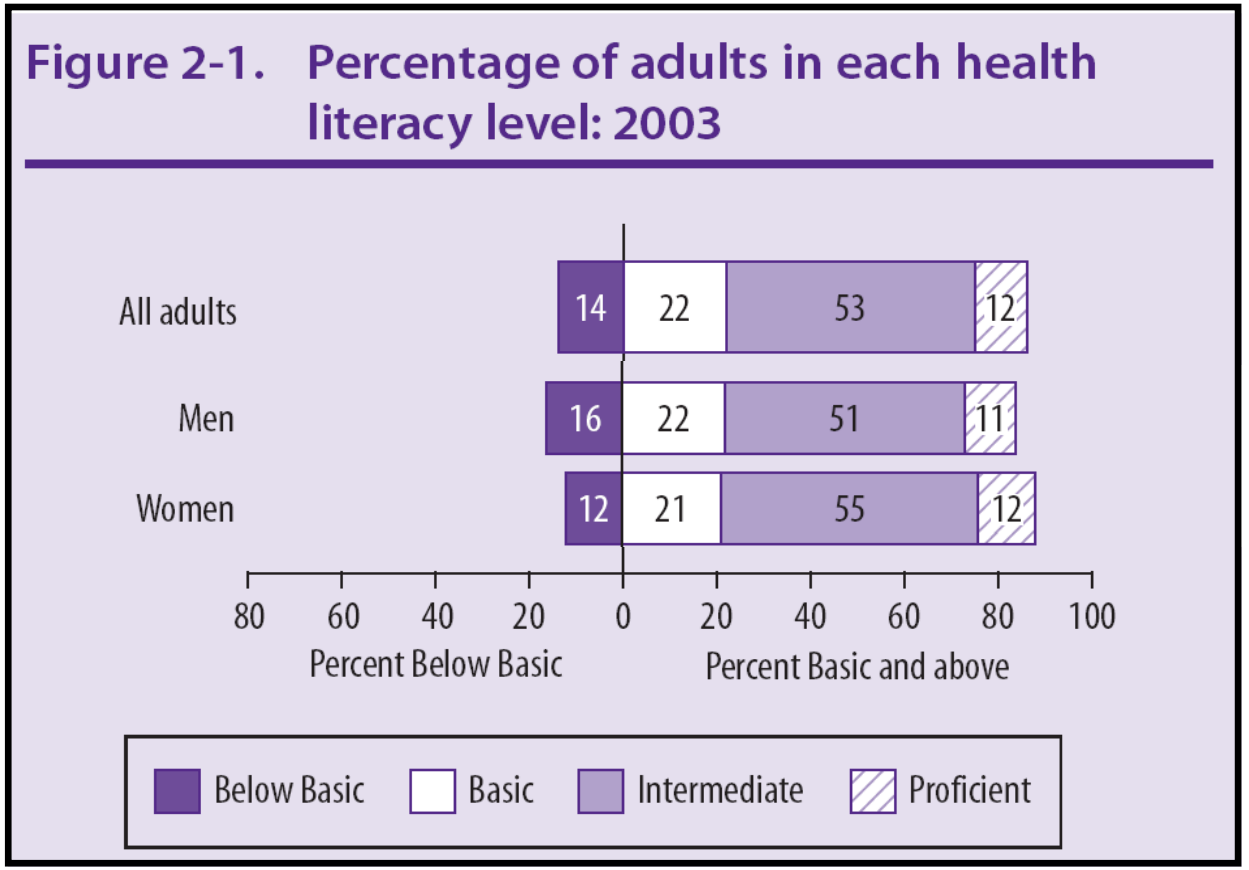
SOURCE: U.S. Department of Education, Institute of Education Sciences, National Center for Education Statistics, 2003 National Assessment of Adult Literacy

Health Literacy: Degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions

- ~1/3 of U.S. adults have limited health literacy
- Disproportionally affects less educated, elderly, poor, or have limited English proficiency

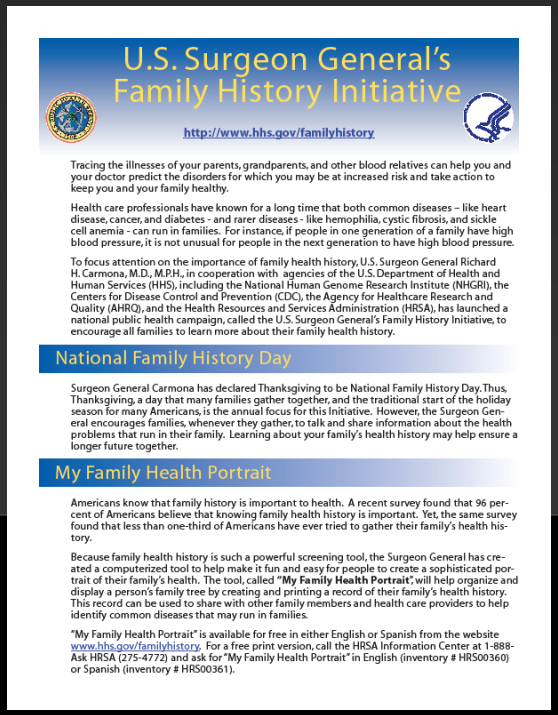


National Assessment of Adult Literacy (NAAL), 2003

Family history tools to increase genetic literacy

If you build it, will they come?

If they come, how good is the data?



U.S. Surgeon General's Family History Initiative

http://www.hhs.gov/familyhistory

Tracing the illnesses of your parents, grandparents, and other blood relatives can help you and your doctor predict the disorders for which you may be at increased risk and take action to keep you and your family healthy.

Health care professionals have known for a long time that both common diseases – like heart disease, cancer, and diabetes - and rarer diseases - like hemophilia, cystic fibrosis, and sickle cell anemia - can run in families. For instance, if people in one generation of a family have high blood pressure, it is not unusual for people in the next generation to have high blood pressure.

To focus attention on the importance of family health history, U.S. Surgeon General Richard H. Carmona, M.D., M.P.H., in cooperation with agencies of the U.S. Department of Health and Human Services (HHS), including the National Human Genome Research Institute (NHGRI), the Centers for Disease Control and Prevention (CDC), the Agency for Healthcare Research and Quality (AHRQ), and the Health Resources and Services Administration (HRSA), has launched a national public health campaign, called the U.S. Surgeon General's Family History Initiative, to encourage all families to learn more about their family health history.

National Family History Day

Surgeon General Carmona has declared Thanksgiving to be National Family History Day. Thus, Thanksgiving, a day that many families gather together, and the traditional start of the holiday season for many Americans, is the annual focus for this Initiative. However, the Surgeon General encourages families, whenever they gather, to talk and share information about the health problems that run in their family. Learning about your family's health history may help ensure a longer future together.

My Family Health Portrait

Americans know that family history is important to health. A recent survey found that 96 percent of Americans believe that knowing family health history is important. Yet, the same survey found that less than one-third of Americans have ever tried to gather their family's health history.

Because family health history is such a powerful screening tool, the Surgeon General has created a computerized tool to help make it fun and easy for people to create a sophisticated portrait of their family's health. The tool, called **"My Family Health Portrait"**, will help organize and display a person's family tree by creating and printing a record of their family's health history. This record can be used to share with other family members and health care providers to help identify common diseases that may run in families.

"My Family Health Portrait" is available for free in either English or Spanish from the website www.hhs.gov/familyhistory. For a free print version, call the HRSA Information Center at 1-888-Ask HRSA (275-4772) and ask for "My Family Health Portrait" in English (inventory # HRS00360) or Spanish (inventory # HRS00361).

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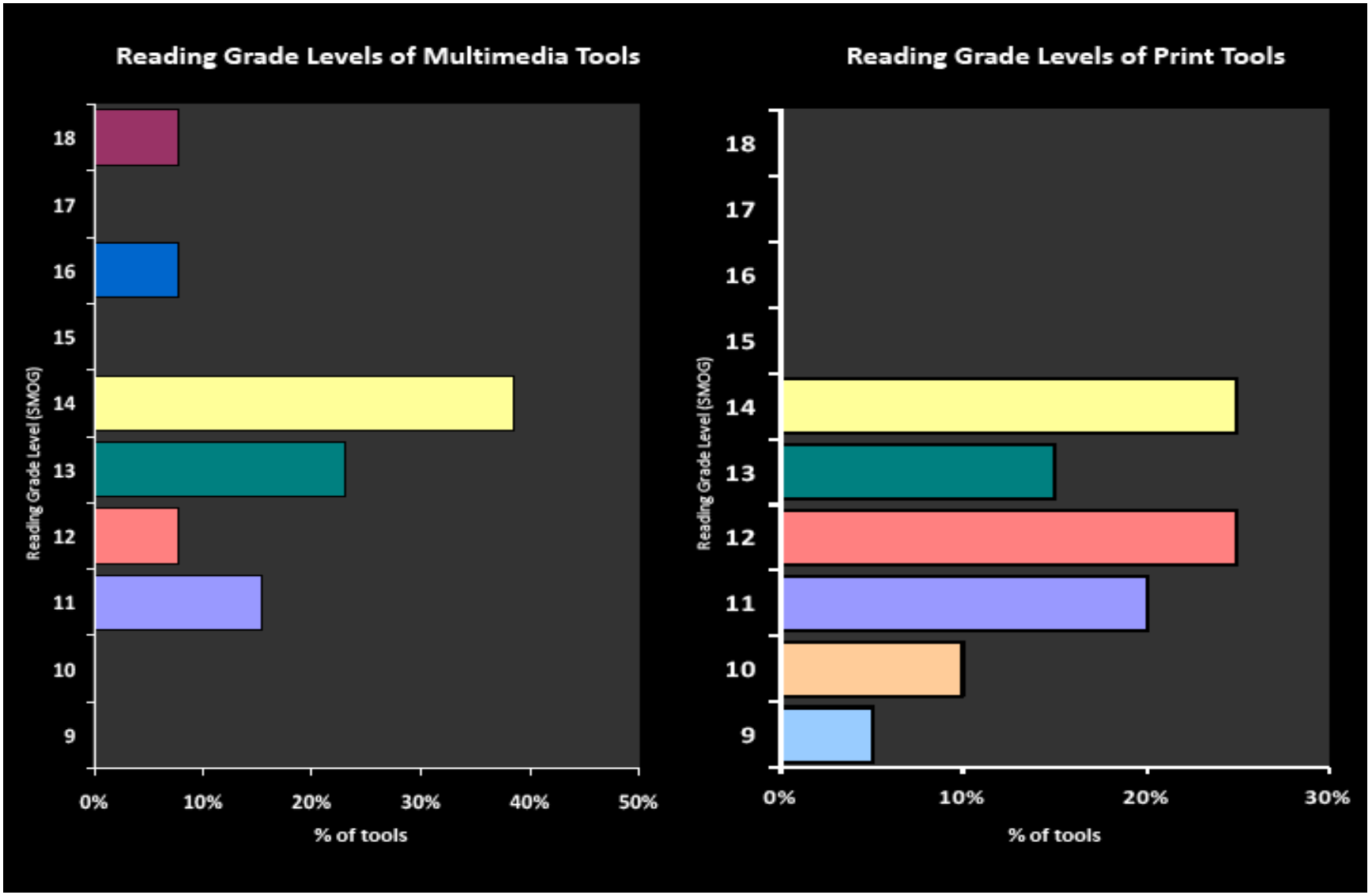
Literacy Assessment of Family History Tools



Wang et al (2011) Public Health Genomics

Validity of family history assessment

Sensitivity results (1st/2nd degree relatives)

MFHP NHGRI validation
(Facio et al., 2010; GIM)

- N=150, 95% white, 67% ≥college grad, 57% >100K
  - Heart Disease: 78%
  - Stroke: 87%
  - Diabetes: 82%
  - Breast Cancer: 84%

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MFHP BU pilot validation
(Wang et al., 2015; GIM)

- N=35, 60% black, 51% ≤HS, 51% <25K
  - **Heart Disease: 51%**
  - **Stroke: 50%**
  - **Diabetes: 22%**
  - **Breast Cancer: 33%**

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Qualitative Feedback

User Testing Interviews (AA=6, L=10)

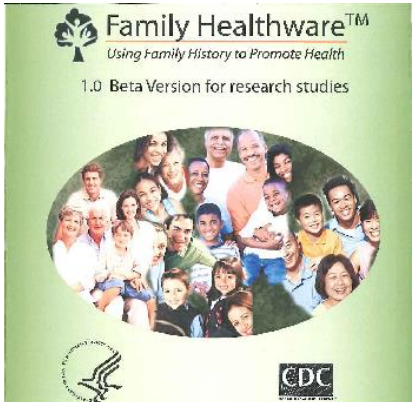
- Like:
  - Generated a report now I could save, maybe share it with someone (104-AA)
  - Everything, but the best part was the family tree (107-L)
- Difficult/confusing:
  - Saving it and going back, pulling up profile (103-AA)
  - Everything, computer was difficult (110-L)
  - Working with the computer (114-L)
  - To get and access (the information) in computer, mouse was a problem (126-L)

Qualitative Feedback

User Testing Interviews (AA = 6)

- Like:
  - I like the way it's put into graphic form. I never thought about me and my mom diagnosed around the same age (124-AA)
- Difficult/confusing:
  - Knowing where to click, the computer itself (117-AA)
  - To figure out why the information did not save for the actual diseases (118-AA)
  - I didn't understand how to add my father and mother (124-AA)

Qualitative Feedback



CDC Family Healthware™ (AA=4)

- Like:
  - Gave print-out of family tree (101-AA)
  - Loved the website at the end (resources), it didn't just leave you hanging (102-AA)
- Difficult/confusing:
  - It was confusing who (had) to be filled out (106-AA)
  - Think back to recall relatives, diseases and conditions (101-AA)

Literacy challenges when using computerized fhx tools

Content

- Number of diseases collected
- Disease terms: hypertension vs high blood pressure
- Who we want history on (extended families, 2nd deg)
- Why certain questions are being asked (how it relates)
- Asking about age – specific vs. range
- Non-blood related family members
- Non-traditional families
- Stigmatized or ‘non-genetic’ conditions

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Literacy challenges when using computerized fhx tools

Navigation

- Mouse/keyboard challenges
- Lack of instructions about what to do, actual task
- Moving between screens, where to go next (auto-advance/save)
- Scrolling to enter more information
- Drop down menus, locating disease terms
- Adding family members
  - linear vs open
- Order of data entry
  - family members first then conditions or reverse?
  - alternating between family member and condition

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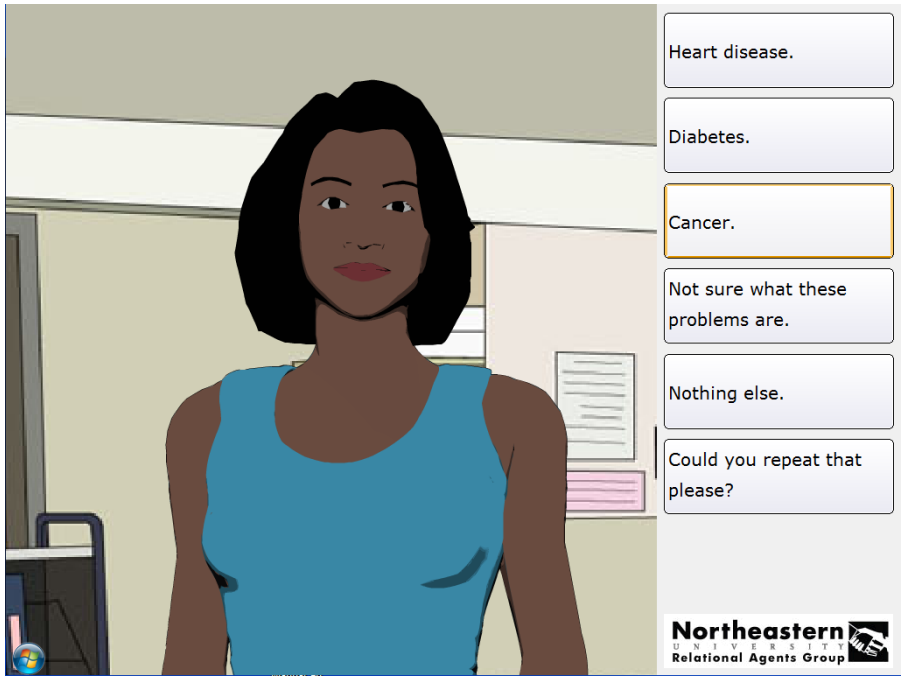
Virtual Counselors

- Computer-animated characters that simulate face-to-face conversation between a patient and a health provider
- Requires minimal language / computer skills
- Use of nonverbal conversational behaviors
- Flexible and responsive, tailored to individual

- Prototype developed to collect family health history information from patients



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VICKY pilot study

Table 2 Evaluation of tools (percentage endorsement)[a]

Evaluation question	VICKY	MFHP	OR (95% CI)	*P* value
1. How easy was it to use the tool?	91%	59%	7.47 (1.90–29.28)	0.0017
2. How easy was it to follow the flow of the tool?	91%	51%	10.07 (2.60–39.11)	0.0002
3. How easy was it to understand the information being asked?	97%	66%	17.74 (2.16–145.95)	0.0007
4. How much do you like this tool?	83%	66%	2.52 (0.82–7.75)	0.1008
5. How likely are you to use this tool on your own?	57%	46%	1.58 (0.62–4.07)	0.3388
6. Would you recommend this tool to others?	83%	49%	5.12 (1.70–15.39)	0.0025
7. Overall, how satisfied are you with this tool?	77%	54%	2.84 (1.01–7.98)	0.0440[b]
8. Overall, how would you rate the quality of the family history tool? (very good/excellent)	62%	46%	1.92 (0.74–5.01)	0.1813

CI, confidence interval; MFHP, My Family Health Portrait; OR, odds ratio; VICKY, Virtual Counselor for Knowing Your Family History.

[a]Percentages reflect those who rated the item either 4 or 5 on a 5-point scale, with the exception of the last item, which reflects those participants selecting either very good or excellent on a 5-point scale. [b]No longer significantly different after adjusting for sex (OR = 2.60; CI: 0.90–7.47; $P = 0.0763$).

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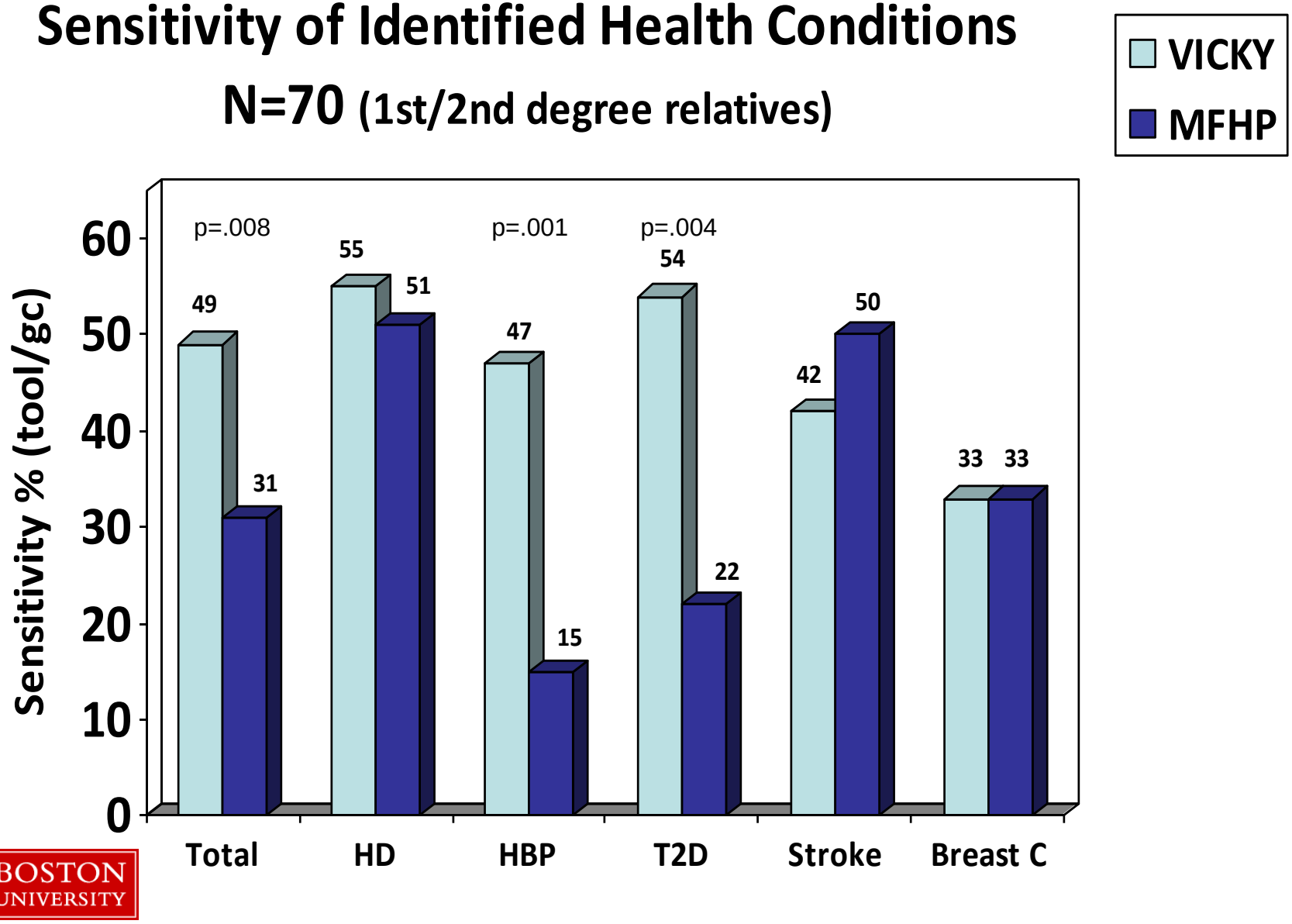
Wang et al (2015) Genet in Med

Sensitivity of Identified Health Conditions

N=70 (1st/2nd degree relatives)



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Wang et al (2015) Genet in Med

Gold standard in fhx documentation?

Cases identified by VICKY but not genetic counselor

- False positives vs. GC omission?
- Stigma?

Condition	False positives
Heart Disease	39%
Type I Diabetes	38%
Type II Diabetes	25%
Gestational Diabetes	0%
Breast Cancer	40%
Colon Cancer	20%
Lung Cancer	57%
Ovarian Cancer	0%
Skin Cancer	0%
Prostate Cancer	40%
Other Cancers	17%
Alcoholism	45%
Asthma	78%
High Blood Pressure	49%
High Cholesterol	58%
Stroke	39%

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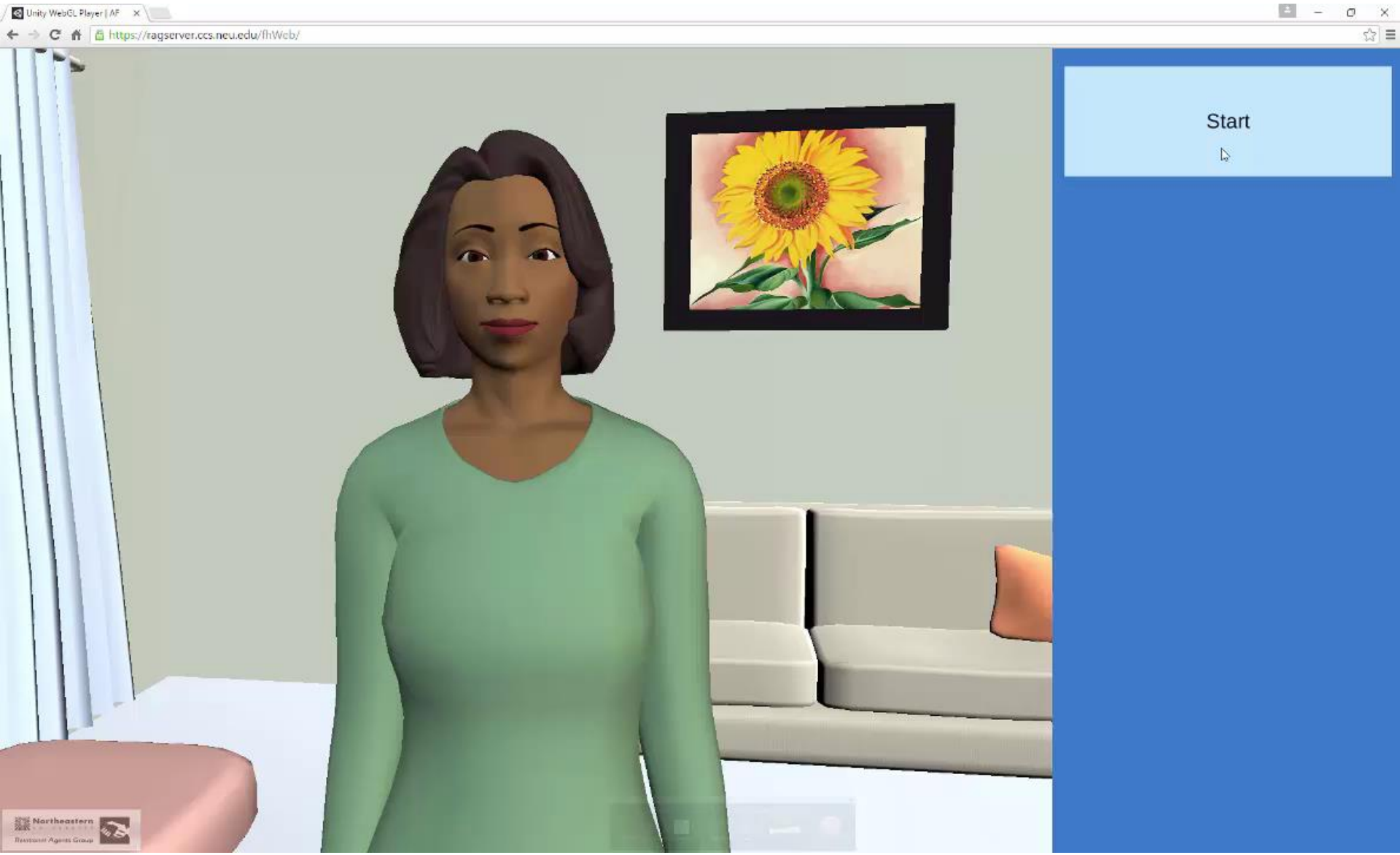
VICKY 2.0


Unity WebGL Player | AF
https://ragserver.ccs.neu.edu/fhWeb/
Start
Northeastern

If you build it, will they come?

- If you build it and it's lousy, no one will use it
- Many of currently available fhx tools have not been validated
- Validation studies have mostly been done on highly educated, white samples with limited generalizability
- Garbage in = garbage out

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Summary

- Genetic (and computer) literacy skills have important implications in the effectiveness of genomics translation
- Develop family health history tools that people can access and use, irrespective of literacy levels
- Remember the person in “personalized” medicine

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VICKY conditions by version

VICKY 2.0	VICKY pilot
Cancer	
Breast cancer	Breast cancer
Colon cancer	Colon cancer
Prostate cancer	Prostate cancer
Lung cancer	Lung cancer
Ovarian cancer	Ovarian cancer
Skin cancer	Skin cancer
Diabetes	
Type 1 diabetes	Type 1 diabetes
Type 2 diabetes	Type 2 diabetes
Gestational diabetes	Gestational diabetes
Heart attack/heart disease	**Heart disease**
High cholesterol	**High cholesterol**
High blood pressure	**High blood pressure**
Stroke	**Stroke**
Alcoholism	**Alcoholism**
	Asthma
Alzheimer's	
Addiction	
Mental illness	
Anxiety or panic disorder	
Depression	
Bipolar	
Schizophrenia	

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